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Love, Intimacy and Sexuality in Nursing Home Residents with Dementia:

An Exploration from Multiple Perspectives

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Colofon

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Love, Intimacy and Sexuality in Nursing Home Residents with Dementia: An Exploration from Multiple Perspectives

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Content

Preface

Cooperation between (nursing home) clinical care practice and an academic collaborative center, based on equality, forms the foundation of this doctoral thesis. Issues surrounding intimacy and sexuality were encountered regularly in dementia care practice. These issues include both 'normal' and 'healthy' sexual behaviors, and 'problem' behaviors or sexual disinhibition, although the distinction between the two themes is rarely recognized. As a psychologist working in a nursing home, I encountered these issues in my daily work. In this practice, direct caregivers observe and initiate discussion of issues they experience in their work. When it concerns intimacy and sexuality, caregivers tend to experience behavior that indicates any need for intimacy or sexuality as problem behavior and therefor bring it up with me regularly. However, my interest was drawn to normal or healthy intimate and sexual behavior, as this behavior was least recognized as such by caregivers. Prejudices and taboos surrounded the theme in direct care practice, which I was convinced were merely caused by a lack of knowledge, insecurity and inclination to act, rather than caregivers being unwilling to provide residents with the care they needed. The same was true in discussion on the theme among indirect caregivers, such as medical doctors (MD) and care management, and a guideline or policy plan to improve the situation was not ready available.

After some research and discussion, I found that scientific knowledge on the theme of normal or healthy intimate or sexual behavior was very scarce. These experiences encouraged me to start a scientific study of this matter. The preparation for this study was performed through reading (scientific) literature and through discussion with researchers and different care professionals, such as direct caregivers and indirect caregivers. The final research question is a result of both preparations.

All the way through the process, research and clinical practice were equally involved in the research project. This was also true for the design of the study and the study procedure. We hope that through this approach the study will contribute both to understanding of the subject and spreading research results and knowledge in clinical care practice. Furthermore, we aimed at increasing practice-based perspectives in research, which will hopefully contribute to the research field and at the same time increase valorization.

General Introduction

Intimacy and Sexuality in the Elderly

Intimacy and sexuality are important aspects of being human, for both young and older people (Droes et al., 2006; World Health Organization, 2006). Taboos and prejudices still surround elderly love, intimacy, and sexuality, as younger people look upon people of age as sexless, or deviant if still intimate or sexually active (Rheaume & Mitty, 2008). The qualifications “dirty old man” for men, or “cougar” for women are examples thereof. However, a growing number of studies contradict the assumption that the need for intimacy and sexuality is just for the young. Wang et al. (2014) reported that 80 percent of their sample of community dwelling people with a partner between 50 and 99 years old were engaged in sexual activity (Wang, Depp, Ceglowski, Thompson, Rock, & Jeste, 2015). Lindau (2007) found that 26 percent of community dwelling people between 75 and 85 were still sexually active. The way people shape this sexual activity was not further defined (Lindau, Schumm, Laumann, Levinson, O’Muircheartaihg, & Waite, 2007). However, when looking at the definition of sexuality by the World Health Organization (2006), this can be diverse and exceeds sexual intercourse alone (Box 1), which was confirmed in a cross-sectional survey including a wide age range (14–94) (Herbenick, Reece, Schick, Sanders, Dodge, & Fortenberry, 2010).

> Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors.

Box 1. The working definition of sexuality (WHO, 2006)

When people age, frequency of sexual activity and sexuality in all its stages (desire, arousal, orgasm, resolution) declines (Tsatali, Tsolaki, Christodoulou, & Papaliagkas, 2010; Wang et al., 2015), and the intensity and possibility for expression is reported to be compromised (Saga Health, 2011). Biological, psychological, and social factors are identified as influencing sexual expression (Delamater, 2012). Firstly, medical (biological) factors include physical changes associated with aging, such as vaginal dryness caused by the menopause in women and erectile dysfunction caused by a slow decline of testosterone production in men. There is, however, little evidence that these changes have more impact on sexual functioning in comparison to social factors such as relationship status and satisfaction (Delamater, 2012). Furthermore,

physical conditions such as hypertension and diabetes, which are more prevalent in older age, affect sexual functioning and expression negatively (Delamater, 2012; Lindau et al., 2007). Also, the use of medications for different health issues is a known disruptor of sexual functioning (Delamater, 2012).

Secondly, psychological issues were found to be of influence. Wang et al. (2015) found that depressive symptoms were a greater predictor for a decline in sexual activity than a decline in cognitive ability. Here, too, (anti-depressant) medications are known negative influencers of sexual functioning and therefore sexual health (Serretti & Chiesa, 2009).

Finally, social factors are of influence—for example, the decreasing availability of a (willing) partner.

However, as mentioned above, intimacy and sexuality are still important for people of age and even more fulfillment in intimacy and sexuality was reported by sexually active elderly people compared to younger people (Saga Health, 2011). This was attributed to a more open mind on the concept of sexuality, as older people do not solely focus on sexual intercourse though include intimate behavior in their experiences.

People with Dementia and Intimacy and Sexuality

Prevalence and Characteristics of people with dementia

The prevalence of dementia is increasing simultaneously with the aging population. It is estimated that, in 2040, 80.1 million people will suffer from dementia worldwide (Ferri et al., 2005). In the Netherlands, 270,000 people are currently living with dementia, a number that is estimated to rise to 690,000 in 2055 (Alzheimer Nederland, 2017).

Although the definition and criteria were slightly changed with the introduction of the fifth edition of the DSM in 2013, dementia is still characterized by “significant cognitive decline in one or more domains of cognitive functioning” (pp.797), such as memory, language, and executive functioning. This cognitive decline results in impairment and independence in activities of daily living which are not explained better by other physical or mental disorders, such as delirium or major depression (American Psychiatric Association, 2000, 2013). The etiology of dementia is diverse. Alzheimer’s disease is the most frequently reported cause of dementia (70 percent) and vascular dementia is the second most frequent (16 percent) (Alzheimer Nederland, 2017).

Intimacy and Sexuality

When people are affected by dementia, sexual expression is compromised. Because of progressive cognitive and physical impairment, the possibilities to express, receive, and experience intimacy and sexuality as wanted become more difficult. It has therefore been suggested that the definition of intimacy and sexuality should be taken more broadly when it comes to people with dementia compared to people of age without dementia (Hajjar & Kamel, 2004). Alongside the biological, psychological, and social factors explained before, the impact of the dementia process also causes changes in the balance of a relationship (Harris, 2009; Mullin, Simpson, & Froggat, 2013), thus changing the way people share intimate and sexual moments. Harris (2009) found through a qualitative study two types of experience of community dwelling couples where one of the dyad had early stage dementia. The first type of experience was one of more intimacy but less sexual activity. Couples did experience a closer relationship on different levels. The second type of experience was one of less intimacy on all levels such as physical intimacy and connectedness in the relationship. It is assumed, however, that intimacy is an important aspect in maintaining a sense of self-identity and self-worth (Tsatali et al., 2010). In a study on experienced quality of life (QoL), intimacy was reported as an important aspect by people with dementia (Droes et al., 2006). It was even assumed that when memory is gone, it is intimacy that may provide a bridge to the past (Harris, 2009; Weeks, 2002).

Dementia Care Setting

When dementia progresses, the cognitive and physical disabilities increase, and the informal care network of a person adjusts its boundaries. Although, in the Netherlands, 70 percent of people with dementia are community-dwelling (Alzheimer Nederland, 2017), people with moderate to severe dementia, whose care needs exceed the possibilities of their informal care network, are admitted to a psychogeriatric unit of a nursing home. In 2014, 83,370 Dutch people with dementia were residing in such a psychogeriatric unit (Centrum Indicatiestelling Zorg, 2014), but due to the aging population, an increasing number of people will have dementia in the future and therefor also this number of people with dementia living in these residential facilities will increase.

Nowadays these psychogeriatric units are group homes consisting of between six and twenty residents. Most often, a number of these groups are combined in one bigger closed unit or building. When people are admitted into a psychogeriatric unit, they are considered incapable of consenting and acting on their own. This is assessed by an independent office that also coordinates individual (governmental) funding of the nursing home facility (in Dutch: Centrum Indicatiestelling Zorg, CIZ). In the context of safety, residents are restricted in their freedom of movement, as for example, they cannot leave the unit without supervision or there is the possibility of using an electronic surveillance system to aid residents

in case of falling. The possibilities of these and other restrictions are described in the Mental Health Act (in Dutch: wet Bijzondere Opneming in Psychiatrische Ziekenhuizen, BOPZ). These measures constrain the freedom and privacy of residents and their possible partners greatly.

In psychogeriatric care units, care is designed in a multidisciplinary and integrated way. Caregivers with a vocational education level (in Dutch: MBO levels 2, 3, and 4) provide direct care. Different therapists, such as physiotherapists, occupational therapists, speech and language therapists, and psychologists, are available to provide indirect care. A specialist MD in geriatric medicine coordinates care and is ultimately responsible for the complete care process.

The Person-Centered Care Perspective

In recent years a paradigm shift has taken place in Dutch nursing home care. A changing view on responsibility with regard to the safety, physical and mental care of residents is recognized (Actiz, 2012). Where a medical perspective dominated for decades, a more person-centered perspective is now spreading, which means that the focal point of care is no longer simply keeping residents healthy and alive. Enhancing QoL is the most important goal of care and this altered view is described with the popular term 'person-centered care'. The concept of person-centered care in dementia care originates from a response to the nonequivalent relationships between residents with dementia and caregivers (Kitwood, 1997). Person-centeredness is defined as a whole person view as well as, maintaining personhood, despite increasing cognitive and physical impairments (Edvardsson, Winblad, & Sandman, 2008). On the one hand, this implies a far broader perspective on residents and the need for expertise on more life domains then just physicality; on the other hand, it implies a more detailed view on the individual and his or her personality, needs and beliefs.

Participant Generation and the Age Gap

Next to all aforementioned influences, the current expression and experience of intimacy and sexuality of nursing home residents with dementia is shaped by their own life history and in a wider perspective, by their generation. Currently, in elderly care residents' year of birth ranges between approximately 1916 and 1960. With regard to generations, a distinction is often made between people who were born before World War II (before 1940–1945) and people who were born after. These generations were born into very different worlds and were brought up in different periods of time. With regard to intimacy and sexuality, this distinction is explicitly relevant. As Tarzia (2013) made clear, the generation born before World War II were in their teens and early twenties in the 1940s and 1950s, and the topic of sexuality was

likely to be a great taboo: “Sex was rarely discussed during this period, and limited sexual education was offered in schools” (Tarzia, Bauer, Fetherstonhaugh & Nay 2013, pp 361). In those days, sexuality was exclusively considered useful for reproductive purposes, and after family completion, people were considered asexual (Neeleman, 2012). People who were born during or after World War II experienced their youth or teen years during the 1960s and perhaps even the early 1970s. In this period, the advent of female contraception (e.g., birth control pills) and effective treatment for sexually transmitted diseases were of great influence in terms of changes in this paradigm. Reproduction was no longer the exclusive purpose of sexual activity and sexual satisfaction became a more important aspect, including after family completion (Neeleman, 2012). Moreover, in later life, people from this generation grew familiar with treatment possibilities for physical sexual difficulties, such as erectile dysfunction (Neeleman, 2012). These new knowledge and developments did not only influence sexuality in peoples’ younger years, also elderly reported increasing quantity, and quality, in sexuality through the years (Beckman, Waern, Gustafson, & Skoog, 2008). It is the expectation that attention to intimacy and sexuality will be even more important for Residential Care Facility (RCF) nursing home care as different and more progressive generations enter the RCF in the upcoming years.

Direct caregivers are at least one or more generations younger then the residents. This age gap, which ranges from one or a couple of years to decades, has been found to influence the attitude of these caregivers with regard to their residents’ intimacy and sexuality, as the older caregivers have more liberal attitudes (Bouman, Arcelus, & Benbow, 2006).

Intimacy and Sexuality in Dementia Care Settings

Dependency and Responsibility: Ethical Considerations

Despite the aforementioned paradigm shift, intimacy and sexuality in residents with dementia remains a complex theme in daily care practice. Archibald (1998) assessed attitudes of managers working in an RCF. Dementia of residents added another dimension to the question whether residents have the capacity to consent to intimate and sexual behavior (Archibald, 1998). Residents with dementia are highly dependent on direct caregivers in many domains of life, including sexuality (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005). Direct caregivers are considered to influence if and how residents express sexuality (Benbow & Beeston, 2012) and caregiver attitude has been defined as one of the barriers to sexual expression of residents with dementia (Hajjar & Kamel, 2004).

Ethical dilemmas and issues of conflicting interest are encountered and discussed in practice. These dilemmas, legal considerations, and theoretical perspectives have also been discussed in previously published papers. Everett (2007),

for example, argued that restriction of and interference in resident sexuality should be kept to a minimum and should always be argued by limited reasons: harm to self, harm to others, and offense to others (Everett, 2007). This rather liberal view on interference seems to contradict the feeling of responsibility of caregivers to provide a safe home for their (other) residents and a safe working environment for themselves (Everett, 2007; Grivorovich & Kontos, 2016; Kamel & Hajjar, 2004; Mahieu, Anckaet, & Gastmans, 2017). Theoretically-oriented papers focus more on (im)possibilities to express intimacy and sexuality in residential care, with regard to legal rights (e.g., such as a lack of privacy) and the conflict this causes with issues surrounding autonomy (Bentrott & Margrett, 2011). Finally, in more policy-oriented papers, the need for a clear policy or guideline has been stressed (Bartlett, 2010).

Sexual Behavior Considered as Problem Behavior

Issues concerning safety, health, and responsibility still surround the subject of intimacy and sexuality in nursing home residents with dementia. This is probably why intimacy and sexuality in residents with dementia is often encountered as problem behavior. Due to cognitive decline, disinhibitions occur in people with dementia, including with regard to intimate and sexual behavior. This, of course, is a burden for the resident, their spouse or family, and the (direct) caregivers. However, it is not always clear whether sexual behavior of a resident can be attributed to hypersexuality (disinhibition of sexual behavior) or 'normal' intimate or sexual need complicated by, for example, disorientation of the resident concerning place, time, or person. For a person with dementia, a situation of physical care can be confusing, as a person (perhaps a beautiful young woman) performs all care tasks as for example undress the person, wash their body with warm water or touch their body while lying in a warm bed. Fulfillment of the shown sexual need of the resident is, of course, not the task of the caregiver. However, to directly assume this behavior as hypersexuality is doubtful. Van Hooren (2011) argued that there is a need for a clear definition of the distinction between normal expression of the need for sexuality and abnormal or 'problem' behavior. So far, this distinction has not been clarified: indeed, it is more difficult than it initially seems, as behavior—the way it is 'intentioned' and the way it is attributed by others—is individually shaped. Furthermore, the client perspective of 'normal' or 'healthy' intimate and sexual behavior has not yet been addressed.

The Client Perspective

The person-centered care paradigm gains importance within Dutch nursing home care, and as a result there is an increasing focus on QoL in dementia care. Consequently, the perspective of residents on their experiences, needs, and beliefs is considered more important. This is the case for a lot of practical topics, such as preferences in daily activities, eating, and clothing. The life history of residents is seen as a guideline for shaping daily care and treatment (Edvardsson et al., 2008). This

is not the case when considering the history with regard to intimacy and sexuality, however. In practice, these themes are sparsely discussed and, if they are, usually discussed in terms of 'problem' behavior. The clients' perspective on their own experiences, needs, and beliefs with regard to intimacy and sexuality are largely ignored.

Also in research, the client perspective is greatly underexposed. This is surprising, considering the private nature of the subject. During the execution of this study, one study on the client perspective was published (Bauer, Fetherstonhaugh, Tarzia, Nay, Wellman, & Beattie, 2013). However, this study included not only residents with dementia, but also residents without dementia. Furthermore, the care settings in which the included participants resided were diverse and not comparable with the care setting (psychogeriatric units) focused on in this study.

Research Objective, Study Design and Thesis Outline

When putting all this together, a topic that seems rather simple—people's need to experience intimacy and sexuality in the way they want—becomes a highly complex topic. Factors such as age, dementia and corresponding cognitive impairment, age-induced physical comorbidities, psychological and social factors, relational changes, a change in living environment and consequently an increase in dependency are all assumed to influence (negatively) the need and possibility to express and experience intimacy and sexuality. How do residents and their spouses make sense of this changed situation? Is there still a need for intimacy and sexuality? And what can RCF organizations do to improve the situation with regard to this matter?

Intimacy and sexuality in people with dementia who live in nursing homes is the theme of this doctoral thesis. We hope to contribute to care practice and the field of research by composing a research question that covers issues from both a clinical practice perspective and a research perspective.
This study was designed as a PhD project addressing the following research question:

> In what way can nursing home residents with dementia, and possibly their partners, be best supported in their wishes and needs with regard to intimacy and sexuality?

A mixed methods and exploratory design was applied to explore intimacy and sexuality in nursing home residents with dementia. Both prior literature, and qualitative and quantitative data were collected and separately analyzed. The thesis is accordingly divided into three sections (A, B, and C). All results are gathered and merged in the general discussion of this thesis.

In part A and Chapter one, a published paper on a systematic literature review is included. The objective was to explore the field of research by reviewing existing published research between 1990 and 2013 on 'normal' intimacy and sexuality of nursing home residents with dementia. The aim was to provide a structured overview of research literature on that theme based on the research question:
What is known through empirical research with regard to intimacy and sexuality in nursing home residents with dementia?
After a systematic study selection and an assessment of the methodological quality of the found papers using the mixed methods appraisal tool (MMAT) (Pace et al., 2012), twelve published papers were included in a qualitative analysis.

In part B (Chapters Two, Three, and Four), the client perspective is included. In Chapter Two, methodological considerations and a guide to the study design with regard to research on the client (resident with dementia) perspective on intimacy and sexuality are presented. The execution of the study was challenging on different levels, and thorough discussions and considerations preceded the complete process. These considerations, and the choices we made, are included, supplemented with examples from our study. Furthermore, a guide to study the client perspective in nursing home residents with dementia is included.

In Chapters Three and Four, the results of a qualitative study on the experiences, needs, and beliefs on love, intimacy, and sexuality of nursing home residents and their partners are presented. These two research questions form the basis of this study:

1. What experiences and needs do nursing home residents with dementia and couples have regarding intimacy and sexuality? If any, what are the needs for assistance, facilitation, or specialized care regarding intimacy and sexuality?
2. What experiences and needs do spouses of nursing home residents with dementia have regarding intimacy and sexuality? If any, what are the needs for assistance, facilitation, or specialized care regarding intimacy and sexuality?

Seventeen interviews in total were held with residents with dementia and their spouses. An analysis of the data was performed separately for people with dementia and couples (Chapter Three and research question 1) and spouses (Chapter Four and research question 2). This distinction was made because of differences in the content and abstraction level of the interviews between the two groups of participants. All analyses were performed according to the Interpretative Phenomenological Analysis (IPA) (Larkin & Thompson, 2012; Smith & Osborn, 2007). This method of analysis enabled us to gather in-depth information from the client perspective and to consider the results in light of the way people make sense of their personal worlds. Understanding the needs and beliefs of people with dementia and

their partners with regard to intimacy and sexuality was the main objective of this study.

Finally, in part C and Chapter Five, a quantitative study is presented according to the following research question:

What contextual factors affect care staff attitude with regard to the sexuality of residents with dementia?

The aim of this study was to determine whether the contextual factors of person-centered care and culture of the organization affect the attitude care staff holds of resident sexuality. Care staff on different levels within the care organization were recruited to participate, as long as they were involved in psychogeriatric nursing home care. Furthermore, more individual factors were included as covariates, such as age, level of education, care organization, and knowledge with regard to resident sexuality.

Finally, in the general discussion, an answer to the general research question is presented. Further interpretation of the findings, the strengths and limitations of the different studies, and implications for future research and for clinical practice are also described.

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Part A Research perspective: a systematic literature review

Chapter 1. Intimacy and sexuality of nursing home residents with dementia: a systematic review

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Abstract

Background: Considering people with dementia, increasing cognitive, physical and environmental impairments can impede the capacity to express and experience intimacy and sexuality. When a move to a residential (nursing) home becomes inevitable, increasing dependency can influence this even more. The aim of the review is to provide a structured overview of all elements of intimacy across the full spectrum of intimacy and sexuality in people with dementia, living in specialist residential care.

Methods: A systematic search and review were conducted. Research published between 1990 and 2013 was identified in the electronic databases Pubmed, PsychInfo and Medline. Inclusion and Exclusion criteria were predefined. Selected studies were assessed on quality, using the Mixed Methods Appraisal Tool (MMAT).

Results: Twelve of 215 initially retrieved unique research publications were selected. A varied range of studies was found; studies differed in design, research quality, searched population and research theme. Different themes emerged: intimate and sexual behavior, knowledge and attitudes, capacity to consent and care culture, staff training and guidelines.

Conclusions: Although results were found in a wide range of intimate and sexual behavior, knowledge, attitudes and needs of others and descriptions of culture in residential and nursing homes, the perspective of residents was lacking in literature. Also a 'protective' care paradigm was found throughout. Future research is needed to highlight resident perspective and develop training opportunities and guidelines for care staff.

Introduction

Intimacy and sexuality are life-long elements of being human (World Health Organization, 2006). When satisfactory, they influence health and quality of life positively (Bouman, Arcelus, & Benbow, 2007; Weeks, 2002). Despite the negative myths, prejudices and stereotypical thinking surrounding late-life intimacy and sexuality a growing number of studies contradict the assumption that needs for intimacy and sexuality are just for the young (Dourado, Finamore, Barosso, Santos, & Laks, 2010; Hajjar & Kamel, 2004; Reingold & Burros, 2004; Rheaume & Mitty, 2008). Although increasing age is associated with a decline in sexual activity, a substantial proportion, 26%, of community-dwelling elderly (between 75 and 85 years of age) reported still being sexually active (Lindau et al., 2007). In a lifecycle model of intimacy, sexuality is considered as just one component, alongside physical contact and intimacy (Delfos, 1994). There is a wide spectrum of intimacy and sexuality described, ranging from emotional intimacy, such as friendships, to sexual arousal and sexual activity. The spectrum consists of both psychological and physical aspects (Basson, 2001). In old age, an even broader definition of intimacy and sexuality seems appropriate (Hajjar & Kamel, 2004). As physical sexual activity becomes increasingly difficult due to physical, cognitive or environmental limitations, intimacy becomes a more important means of maintaining a sense of self, identity and self-worth (Tsatali, Tsolaki, Christodoulou, & Papaliagkas, 2010).

It is not clear whether the proportion of sexually active elderly is as high in elderly with dementia. The prevalence of dementia increases with age, one in eight people over 65 years old has dementia, in over 85 year-olds this percentage has increased to 45% (Alzheimer's Association, 2012). Patients with dementia will experience several cognitive impairments such as memory loss, apraxia and disturbance of executive functions (American Psychiatric Association, 2000), which can influence ability to receive, experience and express intimacy and sexuality. Moreover, geriatric physiological changes in function, anatomy, neurochemistry and pathophysiology, such as diabetes, hypertension and heart disease, also influence sexual desire and sexual function (Tsatali et al., 2010). Finally, availability of a willing partner to experience intimacy or sexuality with may be lower in old age. Loss of a partner or a change in roles within the relationship, due to increasing caring responsibilities, have been shown to influence intimacy and sexuality in people with dementia (Harris, 2009).

As dementia progresses and impairments become more severe it may become necessary for the individual to move to a more protective environment, such as a nursing home. In the USA 3.2 million people live in a protective living environment. More than 60% of them suffer from moderate to severe cognitive

impairments such as dementia (Alzheimer's Association, 2012). When people with dementia reside in a nursing home it can be difficult to satisfy needs for intimacy and sexuality (Hajjar & Kamel, 2004). People with dementia are often less able to verbalize needs and preferences, and observable behavior may be the only way in which their needs are expressed. This means that identification of needs and preferences in this sensitive domain is highly dependent on care staff and Health Care Professionals (HCPs), such as geriatric physicians and social workers (Archibald, 2002; Bouman et al., 2007). Observed behavior is frequently misinterpreted as sexual 'problem' behavior or sexual disinhibition by care staff. In research, this more pathological perspective on intimate and sexual behavior was found to be overrepresented (Rheaume & Mitty, 2008). There is a need for a clear definition of the distinction between normal sexual behavior and abnormal or 'problem' sexual behavior in nursing home residents (Hooren, 2011). A review of studies on healthy, normal intimacy and sexuality seems an appropriate and evidence based foundation for future research and the results could be used to inform care practice.

This systematic review focuses on research on aspects of healthy, normal intimacy and sexuality in patients with dementia who are resident in nursing homes. The aim was to produce a structured overview of all elements of intimacy across the full spectrum of intimacy and sexuality in people with dementia, living in specialist residential care.

Methods

Search Strategy

A systematic search of papers published between 1990 and 2013 was carried out. Papers of interest were expected to be published in biomedical, psychological and health care management journals, so the following databases were searched: PsychInfo, PubMed and Medline. CINAHL database was not searched due to inaccessibility and reported large overlap with the searched databases (Byrne & Neville, 2010; Edhlund, 2006) Synonyms and some additional words were used as (free text) keywords to retrieve relevant articles (Table. 1). The search was performed on October 8th 2013. The search terms (mesh terms and free text words) were selected from three categories: 1) Population (dementia); 2) Intimacy and sexuality and 3) Care setting (Table. 1).

Table 1. (Mesh) Search terms used in search strategy

1. Population AND

#1 Dementia* OR
#2 Alzheimer's disease
#3 Vascular dementia
#4 Geriatric residents
#5 Inpatients
#6 Nursing home residents

2. Intimacy and Sexuality AND

#7 sexuality OR
#8 intimacy
#9 intimate behaviour
#10 sexual behaviour
#11 intimate behavior
#12 sexual behavior*
#13 sexual desire
#14 sexual activity
#15 sexual interest
#16 sexual expression
#17 sexual satisfaction

3. Care setting

#18 nursing home care OR
#19 nursing home
#20 residential care*
#21 long term care*
#22 inpatient care
#23 care unit
#24 institutionalized
#25 institutional care
#26 long term care facilities
#27 care home
#28 dementia care

Note: *Mesh terms used to search PubMed database

Inclusion and Exclusion Criteria

Three authors (TR, KL, PE) agreed inclusion and exclusion criteria consistent with the aim of the study.

Inclusion criteria

- Studies focusing on intimacy and sexuality of people with dementia living in residential and nursing homes and if applicable, their partners;
- Studies focusing on attitudes of care staff, HCPs and management of residential and nursing homes, on intimacy and sexuality in patients with dementia;
- Empirical research: qualitative, quantitative and mixed methods studies;
- Original, peer-reviewed studies written in English.

Exclusion criteria

- Other systematic reviews and statements;
- Studies focusing solely on legal, theoretical and ethical aspects;
- Studies focusing on hyper sexuality, problem or inappropriate sexual behavior and sexual or intimate disinhibitions;
- Studies focusing on abuse, sexual abuse, mistreatment or maltreatment;
- Studies focusing on Parkinson's disease, Huntington's disease, AIDS dementia and Creutzfeldt-Jakob syndrome.

Study Selection and Data Extraction

Figure 1 shows the selection process in a flowchart. In the first selection phase duplicates were removed and all titles and abstracts were screened by one reviewer (TR). Publications which met the inclusion criteria and those which was uncertainty about went forward to the second selection phase. In the second phase two reviewers (TR, KL) assessed abstracts and full text versions of publications independently. Disagreements about inclusion were resolved by discussion between the two reviewers. All references from articles in the second phase (N=43) were assessed (snowball method) by one reviewer (TR) to find more relevant studies. These publications were screened by title, abstract and full text version by the two reviewers, in an identical process.

A predefined table of descriptive information and characteristics was used to provide an overview of the diversity of design characteristics and research focus in the included publications (Table 2). Next, two reviewers (TR, KL) assessed the results in the included publications independently. The structure of the review was determined by this analysis of results and the themes which emerged.

Assessment of Methodological Quality

In health sciences, a substantial proportion of published studies use a mixed methods design (Pace et al., 2012). This was true of the papers included in this review. We therefore chose to assess the methodological quality of research using

the Mixed Methods Appraisal Tool checklist (MMAT; Pace et al., 2012). This checklist consists of 21 criteria divided into six categories: 1) Screening questions (for all types); 2) Qualitative; 3) Quantitative randomized controlled trials; 4) Quantitative non-randomized; 5) Quantitative descriptive; 6) Mixed methods. Mixed method studies and purely qualitative and quantitative studies can all be assessed using this instrument. There are three levels for all MMAT criteria: fulfilled, unfulfilled and unmentioned. All included publications were assessed independently by two reviewers (TR, KL) and disagreements were resolved by discussion. Relative outcome scores and the percentages of these scores are reported in Table 2. In calculating scores we considered unmentioned criteria to be unfulfilled. The conversion of relative scores into percentages was recommended by the authors of the MMAT (Pace et al., 2012).

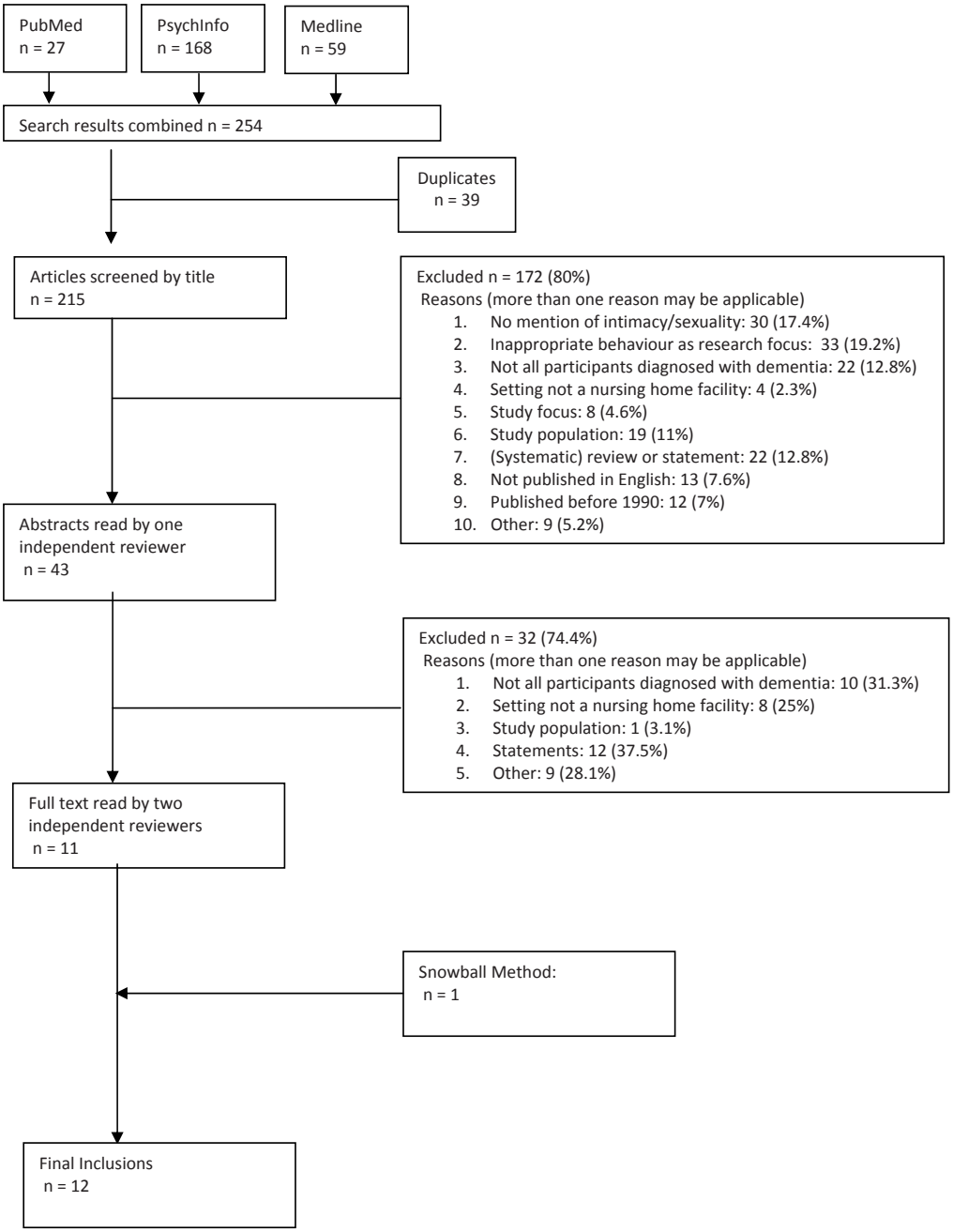

Figure 1
Flow chart of publication selection process.

Results

General findings and quality assessment

The search strategy initially retrieved 215 unique research publications from the databases. Following the selection process 12 unique papers were included (Figure 1). Seven studies were conducted in the USA, three in the UK, one in Israel and one in Northern and Eastern Taiwan.

Four publications were based on quantitative studies, five on qualitative, and three on mixed methods (Table 2). Percentages of MMAT outcomes were calculated to compare the methodological quality of the included publications, these ranged from 50% to 100% (Table 2). Publications with a MMAT score of 50%, i.e. those of lowest methodological quality, are marked (*) in Tables 3 and 4. The MMAT criteria which were least frequently fulfilled by the included qualitative studies and research parts of mixed methods studies were those relating to 'relevance of analyzing processes and 'influencing (bias) by researchers'. There was no detectable pattern to the MMAT criteria most or least likely to have been fulfilled by the included quantitative studies and research parts of mixed methods studies. The criteria least frequently fulfilled by the included mixed methods studies were those relating to 'divergence of qualitative and quantitative data in data triangulation' (Pace et al., 2012).

The included publications varied greatly (Table 2). First, health care systems for the elderly and educational systems for staff varied across countries, which meant that there was variation in the definitions and designations of care facilities, care staff, HCPs and care facility administrators. Second, actual study populations varied greatly among included studies. The participants were mostly proxies, such as care staff (e.g. care workers and registered nurses), HCPs and management or administration staff of nursing homes. In some studies partners, families and legal representatives of the residents also participated. Residents were mostly included as subjects of observation; there were several observational studies. Observations were carried out by researchers, care staff and management. One study reported on the resident perspective on intimacy. Finally, outcome measures varied greatly, depending on the study population and research objectives. In half the studies the instruments used to index outcomes were neither validated nor reliable.

Table 2.
Descriptive information and characteristics

Authors, Year (Country)	**Study Focus** Companionship (C) Love and caring (LC); Romance (R); Intimacy (In); Sexuality (S).	**Perspective** (study population characteristics, *n*)	**Study Design** Quantitative (QN); Qualitative (QL); Mixed Methods (MM).	**Outcome measures** (tools)	Study Quality
Archibald, 1998 (UK)	**Reported behavior/ Attitude** (In; S)	**Management/ HCP** (managers of social work residential homes, *n=23*)	Survey (QN)	**Demographic data;** **Behavior described as sexual** (checklist); **Sexual Expression** (Structured postal questionnaire; Holmes questionnaire; vignettes; short case study)	75% (3/4)
Archibald, 2002 (UK)	**Attitude** (S)	**Staff** (care workers of social work residential homes, *n=6*)	Case study (QL)	**Attitude towards dementia;** **The difference dementia makes when sexuality becomes a component of care.** (interviews)	50% (2/4)
Bullard-Poe et al., 1994 (USA Va.)	**Experiences/ Needs** (C; In; S)	**Residents** (Male residents (MMS >15/30, *n= 45*)	Structured interview (QN)	**Cognitive function** (MMS); **Physical function** (Barthel Index); **Life satisfaction** (LSI-Z); **Social intimacy** (vignettes); **Perceived importance of intimacy** (vignettes).	75% (3/4)

De Medeiros et al., 2012 (USA)	**Reported behavior/ Experience** (In)	**Staff/ Residents** (Staff, *n=14*, residents, *n=31*)	Semi structured interview and questionnaires (MM)	**Cognitive function** (MMSE); **Language comprehension and production** (FLCI); **Severity of dementia** (FAST); **Staff views on residents' relationships** (staff rating matrix); **Ethnographic observations** (field notes, audio and video tapes, coded behaviors)	63.6% (7/11)
DiNapoli et al., 2013 (USA Ala.)	**Knowledge/Attitudes** (S)	**Staff** Employed staff, with at least minimal daily contact with residents, *n=100*)	Questionnaire and Focus Group discussions (MM)	**Staff demographics** (questionnaire; Duke University Religion Index) **Knowledge of AD and sexuality** (Sexuality in Older Adults Questionnaire; Alzheimer's Disease Knowledge Scale; Aging Sexual Knowledge and Attitudes Scale; focus group discussion) **Attitudes on sexuality** (Holmes Questionnaire; Self-designed items on decision making capacity; focus group discussion)	63.6% (7/11)
Doll, 2013 (USA Kan.)	**Reported behavior/ Attitude/ Policy** (S)	**Management/ HCP** (Administrators and Social workers, *n=91*)	Survey (MM)	**Sexual expression; Attitudes, reactions of management, staff, family to sexual behavior; Presence of policies and guidelines** (Self-designed survey with 42 multiple choice, yes/no questions; qualitative comments)	72.7% (8/11)

Ehrenfeld et al., 1999 (Israel)	**Observed behavior** (LC; R; S)	**Researcher** (Observed psychogeriatric patients in 8 nursing homes 90 % classified with stage II dementia, 10 % classified with stage I dementia, *n=48*)	Observation (QL)	**Sexual behavior** (Self-designed observation checklist).	100% (4/4)
Holmes et al., 1997 (USA NY, Minn. and Wisc.)	**Attitude** (In; S)	**Management/ HCP/ Staff** (17 % Staff (administrators), 45 % Clinical (nurses or physicians), 20 % social workers, 18 % 'other', *n=114*)	Survey (QN)	**Attitudes towards resident sexuality** (Holmes Questionnaire)	50% (2/4)
Mayers, 1994 (USA)	**Attitude/Reported behavior/Policy** (S)	**Staff** (Care takers, *n=33*)	Survey (QN)	**Desire for training;** **Reported sexual behavior;** **Views on the effectiveness of various management approaches** (Questionnaire)	75% (3/4)

Tzeng et al., 2009 (Taiwan)	**Observed behavior** (In; S)	**Researcher** (Observed: Male nursing home residents (MMSE 0-23), ***n=12***)	Grounded theory Observation (QL)	**Characteristics and context of sexual behavior** (Observation; informal interviews with formal caregivers, residents and relatives)	100% (4/4)
Ward et al., 2005 (UK)	**Attitude/Observed behavior** (S)	**Staff, Researcher** (Care-workers, n= (pool from) 400;Observed: residents with AD, ***n=17***)	Interviews, textual analysis of care home documentation, care staff diary, observations (QL)	**Staff attitudes and interventions; Gender and (types of) sexual expression** (Interviews with care staff, textual analysis of care home documentation, observation, care staff diary).	50% (2/4)
Zeiss et al., 1996 (USA Va.)	**Observed behavior** (S)	**Researcher** (Observed male patients with a dementia diagnosis, living in institutional settings aged 60-98 years, ***n=40)***	Observations (QL)	**Observed sexual behavior** (Three coded behavioral categories: Appropriate; Inappropriate; Ambiguous sexual behaviors)	50% (2/4)

Notes: HCP = Health Care Professional; Reported behavior = retrospective report; MMS(E) = (Folstein) Mini-Mental State (Exam); LSI-Z = Life Satisfaction Index-Z; FLCI = Functional Linguistic Communication Inventory; FAST = Functional Assessment Staging.

Themes

Various themes emerged from the included publications. First, a clear distinction could be made between descriptions of reported or observed behavior displayed by residents with dementia and reports of the knowledge and attitudes of different stakeholders in the care process. Second, additional themes emerged: capacity to consent; care staff culture; staff training and practice and policy guidelines. Ethical considerations and dilemmas are dealt with under the capacity to consent theme. The culture of care was often mentioned as an explanation or interpretation of staff attitudes was therefore a more implicit theme. The themes which emerged have been used to structure the Results section: 'Reported Intimate and Sexual Behavior', 'Knowledge and Attitudes', 'Capacity to Consent' and 'Care Culture, Staff Training and Guidelines'.

Reported Intimate and Sexual Behavior

Seven of the 12 included publications reported on the intimate and sexual behaviors of people with dementia living in residential nursing homes. Reports of the prevalence of intimate and sexual behaviors in residents were inconsistent. Some researchers reported 'high' prevalence (Holmes, et al., 1997; Mayers, 1994) whereas others reported low prevalence (Ward et al., 2005; Zeiss et al., 1996). A wide range of behaviors was reported, ranging from 'greetings' to 'sexual acts'. As discussed in the Introduction, a wide spectrum of behaviors should be considered under the domain of intimacy and sexuality, especially in the context of elderly people with dementia. One study covered a relatively wide range of the spectrum of intimate friendships, intimacy and sexuality (Ehrenfeld et al., 1999). Following advice from a specialist, they assigned behaviors to three categories: love and caring; romance and eroticism (Ehrenfeld et al., 1999). In this study behaviors were interpreted from a third party (proxy) perspective, rather than the resident perspective. The resident perspective was however considered in a study by de Medeiros et al. (2012). Three studies only reported observed behavior (Doll, 2013; Archibald, 1998; Mayers & McBride, 1998). A variety of categorization schemes were used in the studies and there was heterogeneity in the approach to interpretation of data (Table 3) (de Medeiros et al., 2012; Ehrenfeld et al., 1999; Tzeng et al., 2009; Zeiss et al., 1996).

Table 3.

Reported intimate and sexual behavior and authors' interpretation or categorization

Author, Year	Reported Behavior	Interpretation or categorization
Archibald, 1998	Holding hands (male and female residents) Fondling breasts of female staff (male residents) Public masturbation (male and female residents) Private masturbation (male and female residents) Having a sexual relationship with female resident with dementia (male resident without dementia) Masturbation by a resident in a shared room Soliciting sexual behavior in public Masturbating whilst being bathed Male resident stealing and wearing women's underwear Rape and sexual attack by a male resident on a female staff member	
Doll, 2013	Sexual talk Sexual act Implied sexual act False allegations or abuse Romantic relationships	
Ehrenfeld et al., 1999	Exchange looks Walking together Sitting close together Intimate conversation Dancing Visiting each other's rooms Touching the face Touching hands Hugging Kissing Touching the chest area Touching the pelvic area Sharing a bed Mutual or solitary sexual activity Other sexual activities	• Love and Caring • Romance • Eroticism

Mayers, 1994	Sexual touching of breasts Sexual touching of buttocks Sexual touching of genitals Kissing Hugging that exceeds mere affection Attempted intercourse Mouthing of breasts Attempted oral sex	
de Medeiros et al., 2012	Engaging in greetings Passing comments Conversation which includes reminiscing and joking Eating meals together Attending recreational activities together Finding a way out of the facility together	• Common interest • Intimacy • Reciprocity • Reliability
Tzeng et al., 2009	Holding hands Stroking another person Kissing Undoing another's clothes Rubbing each other's genitals Sleeping together and holding each other on the same bed	• Sexual acts with contact with others
	Trying but not succeeding in stroking or touching another person Staring at another's display of sexuality Acting out sexual desire Verbal sexual provocations	• Sexual acts without contact with others
	Verbal sexual requests Verbal sexual threats	• Verbal sexual behavior
*Zeiss et al., 1996	Sitting close to someone (arms or legs touching) Kissing Stroking someone on the face, hands, or arms Making explicit sexual comments Touching someone other than partner on breast or genitals Touching partner on breast or genitals in public Being in a state of undress outside the bedroom or bathroom Rubbing up against another Touching one's breasts or genitals in public	• Sexually appropriate behaviors • Sexually inappropriate behaviors • Sexually ambiguous behaviors

Note: *Studies assessed with a score of 50% on the MMAT

De Medeiros and colleagues (2012) reported qualities associated with friendship in the interactions and relationships between residents based on interviews with staff and residents. Themes such as 'intimacy' and 'reciprocity' emerged from interviews with both residents and care staff, including references to 'the closeness' of the relationships (de Medeiros et al., 2012). Behaviors such as 'holding hands', 'sitting close to someone (arms or legs touching)' and 'stroking someone on the face, hands, or arms' were also considered in terms of love, caring or intimacy (Archibald, 1998; Tzeng et al., 2009; Zeiss et al., 1996).

Romance or romantic relationships were also observed and reported in residents (de Medeiros et al., 2012; Doll, 2013; Ehrenfeld et al., 1999; Mayers, 1994). These romances were described in terms ranging from 'close friendship' to 'incidents of consensual sexual activity' (de Medeiros et al., 2012; Mayers, 1994) and all were heterosexual encounters. In the reports of male residents intimacy was strongly associated with life satisfaction and contributed to quality of life (Bullard-Poe et al., 1994). All forms of intimacy were reported to be important and most value was attributed to social, nonsexual physical intimacy (Bullard-Poe et al., 1994).

Eroticism was observed by several researchers. The behaviors in this category most often reported by administrators and social workers were 'sexual talk' and 'sexual acts' (Doll, 2013). Sexual acts were also reported and observed by care staff and researchers and included 'having an erection while bathing (men)', 'touching breasts', 'touching buttocks' and 'kissing or petting' (Ehrenfeld et al., 1999; Mayers, 1994). According to management staff and HCPs of residential nursing homes, the four types of sexual behavior which occurred most frequently were 'holding hands', 'fondling breasts of female staff', 'public masturbation' and 'private masturbation' (Archibald, 1998). It is notable that 'holding hands' was considered as 'sexual behavior' by these managers and HCPs, whilst residents and care staff reported the same behaviors as an expression of friendship (de Medeiros et al., 2012; Archibald, 1998). The erotic behaviors least frequently reported were 'inappropriate behaviors', 'false allegations' and 'abuse' (Doll, 2013). This confirms the findings of Zeiss et al. (1996) who concluded that inappropriate sexual behavior is uncommon in dementia patients in residential care generally. There were found differences in the inappropriate or ambiguous sexual behaviors of residents with Alzheimer's disease and those with dementia caused by other conditions, such as vascular dementia. Qualitative differences, such as a higher frequency of provocative behavior and more intentionally sexual behavior in people with vascular dementia, were found (Zeiss et al., 1996).

Various researchers described causes or 'predisposing factors' for intimate and sexual behavior. Tzeng and colleagues (2009) described factors such as 'opportunity', 'cooperative target' and 'personal space without privacy' that may have led to intimate or sexual behavior. According to care staff and researchers 'perceived friendship', 'conversation between residents' and 'close seating positions in the public area' also preceded intimate and sexual behavior (de Medeiros et al., 2012; Ward et al., 2005). Although the term 'cooperative target' may imply nonconsensual intimate or sexual behavior, 'mutual affection' was also considered under this category (Tzeng et al., 2009).

Intimate or sexual behavior was initiated most frequently by male residents (de Medeiros et al., 2012; Ehrenfeld et al., 1999; Mayers, 1994; Tzeng et al., 2009; Ward et al., 2005) and the vast majority of observed behavior was heterosexual (Ehrenfeld et al., 1999). In general, men displayed sexual behavior more frequently than women according to managers and HCPs (Archibald, 1998), although interest in intimate and sexual behavior was reported in both male and female residents (Mayers, 1994; Ward et al., 2005).

Knowledge and Attitudes

Professionals in various roles in residential and nursing homes were the subject of study in 10 of the 12 studies on knowledge of and attitudes to intimacy and sexuality in nursing home residents with dementia (Table 2). Although individuals in a variety of roles were included most participants were female (Archibald, 1998; Di Napoli et al., 2013; Ward et al., 2005). Only two studies included male staff members (Holmes et al., 1997; Ward et al., 2005). Care staff was described as being low paid and low or intermediately educated (Archibald, 2002; Archibald, 1998). There was an age gap between staff and residents, in some cases more than half a century, which implies that an 'intergenerational effect' influenced the knowledge and attitudes of care staff (Ward et al., 2005).

Table 4.
Knowledge and attitudes

Author, Year	Reported knowledge and attitude (Actor)	Interpretation
Archibald, 1998	Sexual behaviors which cause concern: • sexual behavior towards staff • exploitation or coercion • public sexual behavior Reactions to sexual behavior: • discussing with staff • explaining to residents that their behavior is inappropriate • providing privacy • seeking medical/professional advice • seeking permission of family (Managers)	• Acceptability (heterosexual vs. homosexual behavior, dementia vs. absence of dementia, target of the behavior)
*Archibald, 2002	• residents with dementia were seen as not responsible for their actions • staff reported feelings of discomfort and doubt (Care staff)	• Sexual expression is not addressed appropriately due to: lack of training lack of open and informed discussion
	Order of perceived importance: • social intimacy • nonsexual physical • intellectual • emotional • sexual physical Married residents found intimacy more important than unmarried residents. (Residents)	• intimacy contributes to good quality of life
Doll, 2013	Responses of (Care staff): • seek a supervisor • respectfully try to help the resident • follow facility policy • disgust • ignore the issue • panic • notify family • supportive of facility's actions • embarrassment and humiliation at the resident's sexual or intimate behavior (Family members)	

De Medeiros et al., 2012	• Staff reported few friendships • Staff described four bases for friendship: common interest; intimacy; reciprocity and reliability. (Staff) • Only (male) gender (not cognitive function, severity of dementia or language comprehension) was associated with number of perceived friendships. • Residents reported three categories of activity they participated in with friends: communication; meals and recreational activities. (Residents)	• Staff reporting of friendships between residents was not accurate. • Residents did not generally see the facility as home, and therefore did not make friendships.
Di Napoli et al., 2013	• Positive association between scores for knowledge of sexuality and dementia. • Age was positively associated with dementia knowledge scores. • Caucasians, more educated staff and staff who worked in the facility for a shorter period of time had more positive attitudes towards resident sexuality. • Concerns regarding consent capacity and reactions of families of residents were mentioned. • Staff had more negative attitudes towards interactions between same sex couples than opposite sex couples. Responses: • direct intercession • call the family • call a staff meeting (Care staff)	• Staff had neutral attitudes to late-life sexuality in nursing home facilities. • Staff should receive specific instructions on dealing with resident sexuality and sexual expression. • Responses to questionnaires indicated greater openness than focus group discussions.
*Holmes et al., 1997	• Administrators were more conservative than care staff. • Staff training was recommended. (Management/HCP/Care staff)	Generally a positive attitude was reported

Mayers, 1994	• desire for guidelines and training • a gender difference was perceived in sexual interest and touching by residents • responses to sexual aggression • close monitoring • medication • counseling • transferring a resident (Staff)	
Tzeng et al., 2009	Neutral or negative response (Residents) Reputation affected (Staff) Ignorance of behavior (Family members)	• neutral response • negative response • positive response • Reputation influences how the resident is treated by staff.
*Ward et al., 2005	• Sexual behaviors were rare. • Negative, neutral and positive attitudes towards sexual expression were reported. • Male sexual behavior was observed more often and more likely to be deemed problematic. • Male care staff also deemed female sexual behavior problematic. • Responses varied in gravity. • A compulsion to negotiate. • Need to balance the interests of individual residents and other residents. • Older care staff reported that younger, female members found it more difficult to cope with sexual expression. • Heterosexuality was generally assumed. (Staff)	• Little debate about ethical issues. • A 'carer subculture' in which the most significant aspects of behavior or identity determined residents' reputation and influenced how they were treated.

Note: *Studies with a score of 50% on the MMAT

General findings. Care staff reported neutral or accepting attitudes towards intimacy and sexuality in nursing home residents with dementia (Di Napoli et al., 2013; Doll, 2013; Ehrenfeld et al., 1999; Holmes et al., 1997; Tzeng et al., 2009; Zeiss et al., 1996). Managers, HCPs and researchers reported a range of responses by care staff to observed intimate or sexual behavior, including 'checking with another care-worker or supervisor', 'trying to improve resident privacy', 'following the policy of the nursing home' and 'ignoring the behavior' (Doll, 2013; Tzeng et al., 2009; Zeiss et al., 1996). The self-reported responses of care staff included 'direct intercession', 'calling the family' or 'calling a staff meeting' (Holmes et al., 1997; de Medeiros et al., 2012). In some studies feelings of discomfort, disgust, panic or practical difficulties were observed and reported by HCPs, care staff or researchers (Archibald, 2002; Mayers, 1994; Doll, 2013; Ehrenfeld et al., 1999; Holmes et al., 1997). Feelings of discomfort or practical difficulties were generally related to diffusion of responsibility, the gender (usually male) of the resident, fear of legal action against care staff or the residential (nursing) home, concern for the potential 'target' of the behavior and the conservative or traditional background of the residents (Archibald, 2002; Holmes et al., 1997; Mayers, 1994; Tzeng et al., 2009; Ward et al., 2005; Di Napoli et al., 2013; Doll, 2013; Ehrenfeld et al., 1999). Care staff displayed a more negative attitude, sometimes including attempts to conceal or deny the behavior, to certain behaviors including interactions of homosexual couples, (Di Napoli et al., 2013; Ward et al., 2005), erotic behavior (Ehrenfeld et al., 1999), possession of pornographic material (Holmes et al., 1997) or sexual behavior towards care staff (Ehrenfeld et al., 1999; Mayers, 1994).

Selection of research participants was not limited to care staff and HCPs; Archibald (1998) surveyed 23 managers of residential homes in Scotland, most of whom were women. The participants reported a generally liberal view of sexual expression in non-demented residents but a diagnosis of dementia was thought to add 'another dimension', and a less liberal view of intimacy and sexuality in residents with dementia was reported (Archibald, 1998). In total 19 of the 23 managers reported concerns about sexual expression in their residential home. In situations where sexual behavior was directed at staff members, or exploitation was suspected, the managers found it more difficult to manage the situation and ensure that care staff felt comfortable again (Archibald, 1998). Holmes and colleagues (1997) found that managers showed a more conservative attitude towards sexual expression than frontline service delivery staff (care staff).

Research has revealed differences in the openness or seriousness with which care staff discuss intimate and sexual behavior in people with dementia, depending on the context of the discussion, the educational level of the staff member and method used to assess attitudes (Di Napoli et al., 2013; Ward et al., 2005). Di Napoli and

colleagues (2013) found that when responding to questionnaires care staff reported that sexual feelings should be encouraged, whereas when they were asked in a focus group, they advised that such behavior should be ignored. Most care staff did not raise the issue of sexual interests, history or sexual orientation in an admission interview, nor were positive intimate or sexual behaviors generally mentioned in care plans and reports (Mayers, 1994; Di Napoli et al., 2013; Doll, 2013; Ward et al., 2005). More highly educated care staff was more likely to report more general sexual expression than participants with fewer years of education (Di Napoli et al., 2013). In addition, a lack of debate about the issue of intimacy and sexuality in dementia was mentioned as one cause of the denial of sexual and thereby human rights of nursing home residents (Holmes et al., 1997; Ward et al., 2005)

The ability of care staff to observe and report intimate and sexual behavior accurately was questioned (Ward et al., 2005; Di Napoli et al., 2013). First, the accuracy with which care staff identified self-reported friendships among residents was low, even though both residents and nursing staff shared the same definition of friendship (de Medeiros et al., 2012). Second, contradictory statements about recognition of sexual interest and expression of sexuality were made (Holmes et al., 1997; Ward et al., 2005; Mayers, 1994). Finally, there was considerable divergence between the experiences reported by residents and the observation of sexual and intimate behavior reported by care staff, HCPs and managers (Bullard-Poe et al., 1994). Observation skills and attitudes are influenced by several factors. Di Napoli and colleagues (2013) found a positive relationship between age and years of education and knowledge of dementia and sexuality in aging, and an association between knowledge of dementia and knowledge of sexuality. Factors such as ethnicity (Caucasian vs. African American), years of education, years of working experience and knowledge of sexuality also influenced attitudes to sexuality in people with dementia in this research population (Di Napoli et al., 2013). Notably, knowledge of dementia of care staff was found not related to attitude to expression of sexuality in residents (Di Napoli et al., 2013).

The role of religious beliefs in attitude to sexuality in elderly people was investigated. An association between ‘intrinsic’, ‘nonorganizational’ religiosity and knowledge of sexuality was found, indicating that care staff who engaged in prayer less frequently or reported that religion was less important to them tended to have more knowledge of sexuality in general (Di Napoli et al., 2013) and this reflects in reporting of expression of sexuality by residents; care staff for whom religion was less important or who engaged in less religious activity reported more sexual behavior in residents. Care staff working in residential institutions with a religious affiliation was more conservative in their attitude to sexuality than staff in non-religious residential institutions (Tzeng et al., 2009).

There was also considerably heterogeneity in the attitudes of family members and legal representatives to expression of intimacy and sexuality. A majority of family members reacted in a generally supportive way and were supportive of any actions taken by the nursing home. Family members also reported embarrassment and uncomfortable feelings (Doll, 2013). In cases where a women was sexually active, family members tended to feel protective and reacted with concern for their loved one (Ehrenfeld et al., 1999). In cases where a family member in residential care started a new romantic relationship within the facility, family members reported positive feelings about the new relationship (Ehrenfeld et al., 1999).

Gender

As mentioned above intimate and sexual behavior was most frequently observed in and reported to be initiated by male residents (de Medeiros et al., 2012; Ehrenfeld et al., 1999; Mayers, 1994; Tzeng et al., 2009; Ward et al., 2005). There was a notable gender difference in reporting of intimate and sexual behavior by care staff, female care staff were more inclined to report intimate or sexual behavior performed by male residents and often considered this behavior problematic (Holmes et al., 1997; Ward et al., 2005), whereas Ward (2005) found that some male care staff reported more sexual behavior by female residents, which they found in some sense problematic.

A similar effect was found with respect to the perceived sexual orientation of residents. Same sex encounters were observed by care staff and researchers at the friendship and intimacy end of the spectrum, for example two female residents holding hands, (Ehrenfeld et al., 1999; de Medeiros et al., 2012), whereas 70% of observed eroticism and more overtly sexual behavior reported by care staff took place in the context of heterosexual encounters (Ehrenfeld et al., 1999).

Archibald (1998) stated that sexuality in residential care, as in the wider western society, was viewed from a traditional perspective in which 'male dominated heterosexual activity' predominates and female sexuality is often overlooked. Doll (2013) described a variety of attitudes to non-heterosexuality in residential nursing home care. Ward and colleagues (2005) found no reports of sexual orientation in a study of care files. In another survey study 22% of care staff reported being aware of a lesbian, gay, bisexual or transgendered (LGBT) resident, but only a very small proportion of care staff members had collected this information during the admission process (Doll, 2013). Another study reported more conservative attitudes towards homosexual intimate or sexual behavior (Di Napoli et al., 2013). In one study none of the managers and HCPs reported to respond explicitly, but implicit policy ranged from a 'don't ask, don't tell' approach to viewing the admission of LGBT residents as a potential source of problem sexual behavior (Doll, 2013). In only one of the included

studies was a more liberal view mentioned (Ehrenfeld et al., 1999).

Capacity to Consent

In the extant literature, the capacity of people with dementia to consent to intimate or sexual acts is often questioned. Golander and Raz (2000) described this questioning as part of a wider 'halo effect of dementia' in which individuals with dementia are regarded as lacking capacity for any responsibility by virtue of the diagnosis irrespective of their current actual capacity. This effect can subsequently prevent people from making any decision. Archibald (2002) described a more ambiguous image and referred to the construct of dementia as a 'contested site'. Dementia is also viewed as posing diffuse and difficult ethical dilemmas, which have to be managed on an individual basis (Holmes et al., 1997; Archibald, 2002).

Care staff were generally accepting of intimate or sexual behavior in people with dementia, but care staff, HCPs and managers also reported ethical concerns and dilemmas, including legal concerns, safety concerns, gender issues, the issue of whether or not to involve the family, mismatch in cognitive functioning in the residents involved and differing levels of perceived confusion and awareness (Archibald, 1998; Archibald, 2002; Di Napoli et al., 2013; Doll, 2013; Holmes et al., 1997; Ward et al., 2005; Mayers, 1994).

A variety of views on capacity to consent in people with dementia were reported. First, managers and HCPs reported total abstention from intimate and sexual behavior for people with dementia, is the only safe approach (Doll, 2013). Second, neuropsychological evaluation of current cognitive function was suggested as a way of formally assessing capacity to consent (Doll, 2013). Third, handing over responsibility for decisions about capacity consent to family members was sometimes suggested by managers, HCPs and care staff (Doll, 2013; Di Napoli et al., 2013). Finally, care staff considered that a conscious, consistent and explicit statement of consent by the residents involved was very important (Di Napoli et al., 2013); given the symptoms of dementia this is likely to pose a dilemma. Concerns about possible negative comments from spouses and other relatives were also mentioned by care staff (Ward et al., 2005). In spite of these various concerns expressing and experiencing intimacy and sexuality was also perceived as a 'basic human right' (Mayers, 1994; Holmes et al., 1997).

Care Culture, Staff Training and Guidelines

In the publications included in this review care was carried out by care staff working in teams, in residential nursing homes. Obviously, discussion about behavior of residents

takes place in these teams. The reactions of care staff to expressions of sexuality may be influenced by their views on such activity, such as whether it is acceptable, deviant or a consequence of dementia-related brain damage (Archibald, 1998; Archibald, 2002). Involvement in intimate or sexual behavior can affect a resident's reputation within a team of care staff and registered nurses. This reputation of a resident within a 'carer subculture', based on his or her observable sexual behavior, may influence how that resident is treat in general (Ward et al., 2005). Tzeng et al. (2009) reported that some care staff nicknamed residents in a non-respectful way on the basis of their intimate or sexual behavior.

Most included publications made reference to the need for staff training and guidelines on managing the expression of intimacy and sexuality (Di Napoli et al., 2013; Doll, 2013; Holmes et al., 1997; Mayers, 1994; Ward et al., 2005; Archibald, 2002; Zeiss et al., 1996). Meaningful is the notion care staff members endorse this statement themselves, in most studies (Di Napoli et al., 2013; Holmes et al., 1997). Di Napoli and colleagues (2013) emphasized that training should provide an understanding of sexuality and of dementia, in order to reduce the stigma associated with the combination of these themes and improve the attitudes of care staff towards expression of sexuality in people with dementia (Di Napoli et al., 2013). Care staff, HCPs and managers also suggested that training should improve skills relating to the open discussion of sexuality and that special attention should be given to same sex relationships in residential (nursing) home care (Di Napoli et al., 2013; Doll, 2013; Mayers, 1994).

Several facilities had formal guidelines concerning intimacy and sexuality (Doll, 2013) which were viewed as being a 'better than nothing option'. These guidelines or policies usually covered privacy, consent, human rights, responsibility and religious values (Doll, 2013). Lack of guidelines or formal policy was considered a shortcoming and under these circumstances care staff was more likely to view expressions of sexuality as 'problem' behaviors (Archibald, 1998; Holmes et al., 1997).

Discussion

We carried out a systematic review of research on intimacy and sexuality in nursing home residents with dementia to provide an overview of the spectrum of healthy, normal aspects of intimacy and sexuality in this population. We found reports of a wide spectrum of aspects associated with intimacy and sexuality, and several themes emerged.

Reported Intimate and Sexual Behavior

Data on different aspects of intimate and sexual behavior were found. Most studies covered only a small part of the broad spectrum of expressions of intimacy and sexuality, and care staff, HCPs, management or researchers were the source of information. Only one study focused explicitly on the needs of residents with dementia (Bullard-Poe et al., 1994) and included the resident perspective, however, this study sample was exclusively male, which is not representative of the population, in which women are the majority. Literature addressing intimate and sexual behavior generally adopted a rather normative approach and interpretations of observed or reported behavior appeared to be fairly simplistic; known symptoms of dementia were rarely integrated into these interpretations. Behaviors such as 'masturbation', 'sexual talk' and 'kissing' self-evidently imply intimacy or sexuality, but other behaviors such as 'touching hands' (Ehrenfeld et al., 1999) or 'being in a state of undress outside the bedroom or bathroom' (Zeiss et al., 1996) may also be interpreted as an accidental encounter or loss of decorum as a result of dementia. Discussion of predisposing factors or causes of intimate and sexual behavior did not even mention the normal and healthy need for intimacy and sexuality.

Knowledge and Attitudes

We found research on the knowledge and attitudes of workers in various roles in residential care, such as care staff, health care professionals, managers and administrations. Contrary to the expectations of most researchers, care workers reported a generally positive attitude to intimacy and sexuality in nursing home residents. Nevertheless, the literature presents a complex pattern of influences on attitudes. Several characteristics of individual care staff members were found to influence attitude to the expression of sexuality by residents. The attitude of care staff was also influenced by various characteristics of the resident involved, such as gender, severity of dementia and conservative background. Several behavioral factors influenced the attitude of all residential care professionals. Cases in which sexual behavior was directed towards care staff or other residents were mentioned, but the diffusion of responsibility was also an important concern (Archibald, 2002; Doll, 2013; Ehrenfeld et al., 1999; Holmes et al., 1997; Mayers, 1994). This diffusion of responsibility was described as a complex implicit dilemma, were care roles are

confused with overtaking complete responsibility of the resident with dementia. Homosexual behavior and more explicitly sexual behavior attracted the most conservative reactions. References to the need for staff training and guidelines were ubiquitous; it was suggested that training should improve knowledge about intimacy and sexuality in nursing home residents with dementia, and thereby encourage a less conservative approach.

Gender

Gender was a major issue in the expression of intimacy and sexuality in nursing home residents. This can be concluded based on mere implicit statements and comments found in literature, as it was never reported as a main result of a study. This raises questions of gender positions in residential nursing home care. In the observational studies we reviewed intimate and sexual behavior was usually initiated by men and was more frequent in men. Consequently, a result found by Ward and colleagues (2005) is noteworthy; this study found that female care staff reported that male residents performing more sexual behavior and the female care staff was more inclined to perceive male residents' sexual behavior as problematic, whilst for two male care staff members the opposite pattern was found (more sexual behavior in female residents, female residents' sexual behavior more likely to be perceived as problematic). Further study of this gendered pattern of observation and labeling of behavior would be of interest from both research and practitioner perspectives.

Capacity to Consent

The capacity of people with dementia to consent to any type of intimate or sexual behavior was also considered to be important. This ethical challenge was described in several ways. Capacity to consent was of particular concern to care staff, HCPs and care management when there was uncertainty about the level of cognitive functioning. Several approaches to a formal or 'objective' evaluation of competence were suggested. We conclude that ethical issues should be addressed on a case-by-case basis, taking account of the basic human right of people with dementia who are resident in a nursing home to intimacy and sexuality.

Limitations

Search strategy and inclusion. Only 12 of the 215 publications retrieved in the first phase of the search met all the inclusion criteria. The majority of the research publications were retrieved from PsychInfo. Fewer publications were retrieved from Medline and PubMed. Also, CINAHL database was not searched due to inaccessibility and reported large overlap with the searched databases (Byrne & Neville, 2010; Edhlund, 2006).The small number of relevant publications and the limited sources (mainly PsychInfo) suggest that this is a neglected research area, particularly in medical science.

A substantial proportion of the retrieved publications where excluded owing to ambiguity about the nature of the residential care facility. The heterogeneity of elderly health care systems worldwide is one explanation for this. With the exception of the study by Tzeng and colleagues (2009) all the studies included were conducted in wealthy, Western countries; this means that a large part of the world is not represented in this literature. We also failed to find any reports of studies conducted in the Netherlands during the search process.

Study quality. Study quality was assessed using the MMAT. Four of the included papers achieved a MMAT score of 50%; the remaining eight had higher scores. The MMAT was developed recently (2012) and is not yet in widespread use amongst researchers. The MMAT can be used to assess the quality of qualitative, quantitative and mixed methods studies and thus may enhance the consistency of quality assessment in reviews which include papers using different designs.

Half of the studies included used neither validated nor reliable measurement tools. Most researchers used survey or observation tools of their own development. This is an indication that more research is needed in this area. Qualitative, individual based research seems the most appropriate approach to investigating the resident perspective, which is currently the least represented in the literature.

Implications for Future Research and Clinical Practice

This overview has provided a description of intimacy and sexuality in people with dementia in nursing home care, addressing the issues of the spectrum of behavior, knowledge and attitudes, gender difference and capacity to consent, which should inform future research and practice.

The need for staff training and guidelines was mentioned repeatedly in the literature. Current levels of knowledge of intimacy and sexuality and the observation skills of care staff were questioned (Ward et al., 2005; Di Napoli et al., 2013). Knowledge was found to influence attitude to expression of sexuality (Di Napoli et al., 2013), which suggests that increasing knowledge might lead to a beneficial change in attitudes. As well as improvements in individual knowledge and skills, a need for training at the level of the care team is implied by references to a ‘carer subculture’ (Ward et al., 2005) in which residents’ reputations may be based on their expressions of intimacy and sexuality. Openness to discussion and a more liberal view amongst stakeholders in general are probably prerequisites for altering the subculture in care staff teams. This would allow misconceptions about intimacy and sexuality in the elderly people with dementia, to be addressed more easily; this would hopefully lead to improvements in the quality of life of nursing home residents.

Finally, we conclude that the resident perspective is neglected in the extant literature. In the light of the WHO definition recognizing sexuality as an important, lifelong aspect of human life, the lack of firsthand evidence from people with dementia living in a residential nursing home on this deeply personal and private aspect of life is an important gap in current understanding of intimacy and sexuality.

Conclusion

The perspective of the residents themselves was rarely mentioned in the context of any of the themes which emerged from this review. Given that intimacy and sexuality is a deeply personal, private matter this is rather striking. Intimacy and sexuality are considered to be lifelong elements of being human and their influence on quality of life is recognized (World Health Organization, 2006; Weeks, 2002) which makes this lacuna the more remarkable.

The guiding principle of care in dealing with intimacy and sexuality in residents with dementia, based on the studies included in this review, is best described as 'protective'. Care staff, management and family members try to prevent physical or mental abuse. Some researchers described this protective approach as treating residents like children (Doll, 2013; Archibald, 2002). The dependency relationships between residents and care staff seems to contribute to this protective approach, the 'intergenerational effect' (Ward et al., 2005), which would appear to imply a rather different relationship, notwithstanding. In other publications the 'halo effect of dementia' (Golander & Raz, 2000) was suggested as a potential cause of this protective approach (Archibald, 2002).

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Part B Including the client perspective: a qualitative study

Chapter 2 A person-centered approach to study intimacy and sexuality in residential care facility (RCF) residents with dementia: methodological considerations and a guide to study design.

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Abstract

Background: The person-centered perspective of residential care facility (RCF) residents with dementia with regard to their intimate and sexual lives is largely neglected in research.

Objective: We aim to provide methodological considerations and reflections on a performed qualitative study. Recommendations and a guide to study design are provided to inform and encourage future research on the inclusion of people with dementia as participants.

Methods: Methodological recommendations and reflections are described in chronological order of the procedure. Fragments of interviews are included for further illustration and clarification.

Results: Considering preparation, close involvement of clinical practice, and extensive deliberation regarding study design tended to be important. Considering procedure, investment in contacts with clinical practice and authorized representatives; an introduction meeting; person-centered inclusion and consent; profound skills in interviewing participants with dementia; and flexibility in data collection were proven of importance. Considering data analysis and study quality, including field notes and aiming at a balance between study quality and practicability to enhance study 'rigor' were found important.

Conclusion: Including the person-centered perspective in research on intimacy and sexuality of RCF residents with dementia, is challenging and takes a flexible and creative approach. It is, however, worthwhile to close the gap in literature.

Introduction

Simultaneously with the aging population, the prevalence of dementia has increased. Worldwide estimations predict that in 2040, 80.1 million people will suffer from dementia (Ferri et al., 2005). Today 256,000 people in the Netherlands suffer from dementia, and this figure is expected to rise up to half a million in 2050 (Alzheimer Nederland, 2014). In 2013, a total of 80,555 people with dementia lived in psychogeriatric care units within Residential Care Facilities (RCF) in the Netherlands (Centrum Indicatiestelling Zorg, 2014).

In this psychogeriatric RCF care in the Netherlands, a paradigm shift is taking place (Actiz, 2012a). While medically-oriented views dominated care in the past, a more person-centered view is now expanding. Consequently, contributing to the Quality of Life (QoL) of residents with dementia and their (possible) partners has become a key objective for RCFs, in addition to ensuring safety and providing physical care (Actiz, 2012b; Elias & Ryan, 2011). However, it is not clear whether the QoL oriented care also includes the domain of intimacy and sexuality. Instead, professional caregivers may tend to regard these topics mostly as a purely private matter. Moreover, concerns and complex dilemmas concerning responsibility, consent capacity, and the willing balance between safety and security, and QoL are frequently reported and recognized by Dutch professional caregivers (Hoogeveen & van Waarde, 2016).

Despite increased research into the person-centered perspective in health care, little has been done on the theme of intimacy and sexuality (Roelofs, Luijkx, & Embregts, 2015). This seems remarkable, especially since this theme is so deeply personal. In previously published papers, the person-centered approach has been stressed as one of the major aspects in this field of research (Bentrott & Margrett, 2011; Murphy, Jordan, Hunter, Cooney, & Casey, 2014; Tarzia, Bauer, Fetherstonhaugh, & Nay, 2013). Therefore, both in content and in study design, the person or participant should be the starting point of all considerations.
This is why we composed a qualitative study to explore the experiences and needs of RCF residents with dementia regarding their love, intimate, and sexual lives. In this paper, we aim to provide insights into the methodology of this study and reflect on its design, procedures, and outcomes. We will also provide a guide to study design based on ideas arising from these methodological considerations. With these insights and guide, we hope to inform and encourage future research on how to include the person-centered perspective for people with dementia.

First, the (theoretical) background is detailed; this was the basis for this study and had significant influence on the design of the data collection. Second, methodological considerations and reflections are described. In this chapter, the methodology of the study is presented, reflections and considerations on the design and execution of the study are described, and both are illustrated using examples

from research practice. Third, arising from the considerations, experiences, and reflections, recommendations, and a guide for future studies is composed. We end with a short conclusion.

Background

The World Health Organization defines sexuality as follows:

"Sexuality is a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors." (World Health Organization, 2006).

So, despite negative myths and prejudices, intimacy and sexuality remain important for people in old age (throughout life) and is defined as a far broader concept than sexual intercourse alone (Hajjar & Kamel, 2004; World Health Organization, 2006). Although expression, intensity, and frequency of sexual activity can change across the lifespan (Tsatali, Tsolaki, Christodoulou, & Papaliagkas, 2010), Lindau et al. (2007) found that 26% of community dwelling adults between 75 and 85 years of age reported being sexually active (Lindau et al., 2007). Even more fulfillment in intimacy and sexuality was reported by sexually active elderly people compared to younger people, despite the variation in the intensity of the sexual activity (Saga Health, 2011). That older people have a more open mind on the concept of sexuality was suggested to be a factor in this difference between young and old, as they do not solely focus on intercourse, and they tend to include intimate behavior, such as hugging and kissing in their concept of sexuality (Benbow & Beeston, 2012).

Unfortunately, old age is often accompanied by poor health and illness. Dementia is one of the illnesses with an onset that occurs mostly late in life. Although associated with different somatic conditions, dementia always includes memory loss, and eventually a decline of all cognitive and physical functions (American Psychiatric Association, 2000). In addition to dealing with physical and cognitive impairments, suffering from a chronic and deadly disease can cause a decline in QoL itself (Lawton, 1999; Tsatali et al., 2010). Dementia-specific impairments sometimes induce a necessary move into an RCF. This move impacts the lives of people with dementia even more and can be a reason for further decline in QoL (Gonzalez-Salvador et al., 2000). Among many reasons, lack of privacy was found to be a cause for this decline (Gonzalez-Salvador et al., 2000). In that perspective, it is conceivable that intimacy and sexuality cannot be experienced in the same way people were used to when

living (together) in their own home (Hajjar & Kamel, 2004). In addition to the privacy barrier, Hajjar and Kamel (2004) suggest other physical and environmental barriers to sexual expression in RCFs, based on a literature review mainly of proxy studies.

Despite these barriers (Hajjar & Kamel, 2004), intimate and sexual behavior is observed in RCF residents with dementia (Archibald, 1998; de Medeiros, Saunders, Doyle, Mosby, & Van Haitsma, 2012; Doll, 2013; Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999; Mayers, 1994; Tzeng, Lin, Shyr, & Wen, 2009; Zeiss, Davies, & Tinklenber, 1996). The interpretation of these reported behaviors varied greatly between the various studies. Perceived models of care, views on intimacy and sexuality, aim of the study, and perhaps the researcher's individual point of view seem to be factors in these differences. There is, for example, research that focuses on sexual problem behavior and inhibitions (Tsatali et al., 2010), research that includes the responses to intimate and sexual behavior of other residents (Tzeng et al., 2009) and theoretical perspectives and ethical considerations (Bartlett, 2010; Bentrott & Margrett, 2011; Everett, 2007; Kamel & Hajjar, 2004; Mahieu & Gastmans, 2012). In addition to this small body of literature, there is some attention given to the attitudes, perspectives, and education of care staff in research (Benbow & Beeston, 2012; Di Napoli, Breland, & Allen, 2013; Hajjar & Kamel, 2004; Holmes, Reingold, & Teresi, 1997; Tsatali et al., 2010; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005). Interest in this domain is justified, as nursing home residents with dementia are extensively dependent on their professional caregivers in the specialized psychogeriatric RCF care units. Attitudes and perspectives of said professional caregivers can influence if and in what way residents can express sexuality (Benbow & Beeston, 2012; Hajjar & Kamel, 2004).

Methodological considerations and reflections

Current study

The described study was part of a larger research project, in which we aimed at exploring the experiences and needs of RCF residents with dementia and their spouses, concerning intimacy and sexuality. It was conducted in 2015-2016. Only the study section, which focused solely on RCF residents with dementia, is described below. Dutch RCF residents with dementia were included (see Table 1). These people live in specialized units that contain about six to ten residents in which (small scale) high intensive, 24-hour care is provided. Participants were recruited from three RCFs located in the south of the Netherlands (North-Brabant). The data collection consisted of eight interviews, which yielded rich data.

Various aspects of the study were given extensive consideration. For example, as we expected a very small sample size due to the characteristics of the participants and the topic of research, extensive consideration was given to the recruitment, inclusion, and consent process. This was also done in order to shape all

steps of the research process in the most person-centered way. In the next section, these considerations will be described and explained. During the execution of the study, not all considerations and choices turned out as expected, and in some areas, adjustments were made during the process. Experiences and reflections on this process are also described below.

Study design

A qualitative research design was chosen; specifically, the study was designed according to the Interpretative Phenomenological Analysis (IPA) (Larkin & Thompson, 2012; Smith & Osborn, 2007). This design and analysis methodology was developed to enable researchers to explore people's experiences, but it also allows a detailed exploration of the way in which people make sense of their own personal worlds. The methodology has been previously used in health psychology research (Brocki & Wearden, 2006; Larkin & Thompson, 2012).

Additional design details were thought through extensively, because of the population under study and the subject at hand. This was done by consulting with experts in clinical practice and by organizing two group discussions to elaborate on the design details and specific ethical considerations. For example, the content of the information letter (Appendix 2), the introduction meetings (Figure 1.), the topic list and question schedule (Appendix 1), and the consent procedure for residential participants were discussed and developed by the research team together with clinical practitioners. Professional caregivers, a care manager, and a psychologist working in an RCF psychogeriatric care unit attended the group discussion.

Through the combination of designing the study using the IPA methodology and consulting clinical practitioners, a set of rich data, consisting of both transcriptions of verbal information and field notes of non-verbal information was obtained.

Ethical approval. The research proposal was first submitted to the Medical Research Ethical Committee (MREC) in Brabant (Province of the Netherlands), to assess the legal position of this research. In the Netherlands, the Medical Research Involving Human Subjects Act (Central Committee on Research Involving Human Subject, 1998) governs and controls all (medical) research involving human subjects. Although the targeted participants (people with dementia living in RCF psychogeriatric units) are considered legally incapacitated to consent in participation of scientific research in the Netherlands, and the subject of intimacy and sexuality is considered very private and personal, the MREC decided that this Act was not applicable to this research. The research proposal was consequently submitted to another (lower order) ethical committee. Approval was granted by the ethical committee of Tilburg University (reg. nr. *EC-2014.27*).

Procedure

Recruitment. A stepwise recruitment process was performed (see Figure 1). First, in the identification phase, a list of potential participants was provided to the researchers by the participating RCF organizations. Close contact between the researcher and the participating organizations, especially the secretary offices, was very helpful in this step of the process.

Second, information letters were sent to authorized representatives of the residents. Due to the considered legal incapacity of the residents suffering from dementia, (informed) consent is needed from an authorized representative before the resident can enroll in scientific research. Partners, children, or other relatives of the resident provided this authorized representation. In some cases, a friend of the resident or legal professional served this role. Through the information letters, the authorized representatives were invited to enroll the person they represent for participation in the study.

Third, in the cases of no response, the researcher (TR) made a follow-up call two weeks after the letter was sent, as was stated in the information letter. In practice, it served as an opportunity for different authorized representatives to discuss their doubts and considerations on enrolling the resident they represented. The actual contact proved beneficial to obtaining sufficient participants for the study, but also in promoting understanding by the researchers of the considerations and dilemmas of the authorized representatives. In hindsight, we assume that authorized representatives were even more precautious in enrolling the person they represent than we had expected. This seems understandable, as it is difficult to decide for another person, especially one who suffers from dementia, to participate in scientific research, particularly on the topic of their intimate and sexual lives.

Inclusion. Introductory meetings were arranged to assess the abilities of the enrolled resident and to decide whether inclusion was possible. The authorized representative, the researcher (TR), and a responsible (professional) caregiver of the RCF were present at these meetings. The responsible caregiver is a member of the unit care staff who is the contact point for resident and the authorized representative. People with dementia who reside in 24-hour psychogeriatric care units are impaired in different cognitive and physical areas. To include these residents in qualitative research in which the data collection consists of semi-structured interviews, specific cognitive and physical abilities have to be sufficient. However, while some people suffer from great communicative impairments, others suffer from memory or executive impairments but are not impaired in their ability to articulate their experiences. Furthermore, the manifestations of impairments and their severity are very individual, and the variability over short periods of time can be great. For these reasons, no objective operationalization of the (dis) abilities was performed. Instead, the impression and view of the authorized representative and the responsible

caregiver guided the inclusion process. Some guidelines were followed before the inclusion: residents suffering from moderate to severe communication impairments and residents with severe attention, concentration, and frequently occurring behavioral difficulties were not included.

In this study, no exclusion was performed based on the information obtained in the information meetings. The authorized representatives tended to estimate the abilities of the person they represent sufficiently to decide whether an interview on intimacy and sexuality was possible. However, the inclusion criteria could have been of influence on the results of the study, as only a small portion of the total residential population was able to participate.

Consent. Also during the introduction meeting, written informed consent from the authorized representative was obtained and the procedure for informing and obtaining written informed consent from the resident was discussed. To facilitate the involvement of the resident in the 'ritual' of informed consent (Dewing, 2002), the consent procedure was adapted to the individual resident. A two-step procedure in consent (consent 2 and 3 in Figure 1) was performed. The first step consisted of one of the three consent scenarios (scenarios A, B, C; see Figure 1) and took place two weeks prior to the interview. The choice between one of these scenarios was made during the introduction meeting, but in all scenarios the presence and participation of the resident was most important. Although most respondents (conceivably) could not remember the information for a period of two weeks, a conventional procedure was chosen, where information of the study is provided in advance of the study to all possible participants (Dewing, 2002; Murphy et al., 2014). The second consent step was performed just before the interview started. Again, the content and procedure information was provided to the residential participant and consent to proceed with the interview was requested. During the study, all possible participants consented on both occasions and decided to participate.

Population.

A (convenience) small sample size was obtained (see Table 1), which is both consistent with our expectations and the IPA design requirements (Larkin & Thompson, 2012; Smith & Osborn, 2007). Eight interviews were performed (see Table 1). To obtain a diverse group of people for this study, within the population, no exclusion was performed based on age, sex, marital status, sexual orientation, level of cognitive abilities, or ethnic background. This resulted in a sample of individuals with dementia who were single, or widowed; one couple of two residents with dementia who lived together in the RCF; three couples of whom one is a resident with dementia and the other partner is community dwelling. All participants were heterosexual. The participants did not receive financial compensation for participation.

Table 1.

Participant characteristics

	Gender of resident with ementia	Years of marriage	Relationship status
Couples			
AB	M*	17	Unmarried
CD	F**	unknown	Married
EF	M*	50	Married
FG	M/F***	48	Married
Individuals			
A1	F**	-	Widow
A2	M*	-	Single
A3	M*	-	Widower
A4	M*	-	Widower

Notes: *The resident with dementia was male;

**The resident with dementia was female;

***Both the male and female dyad of the couple are residents with dementia

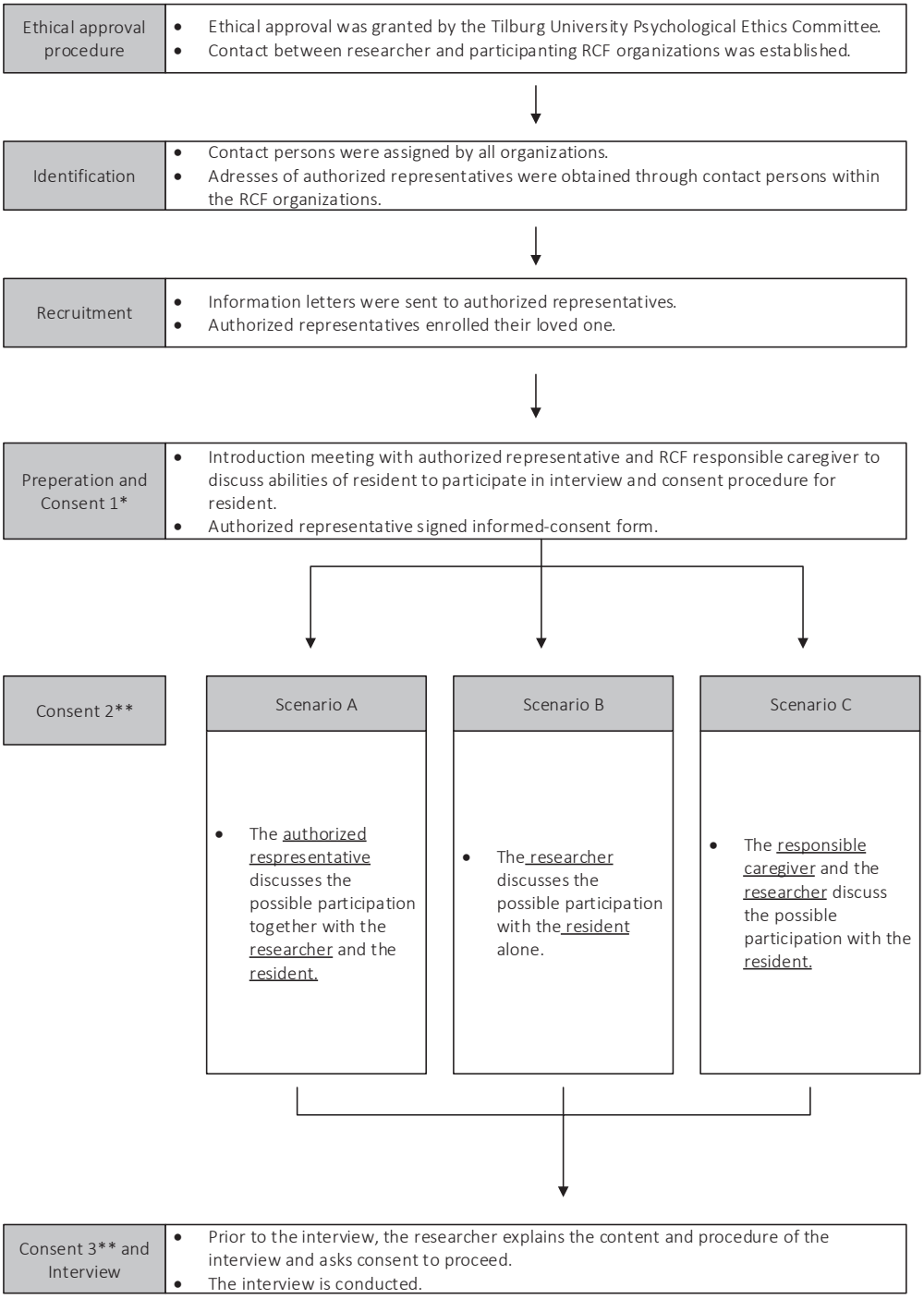

Figure 1. Recruitment, Inclusion and Consent Procedure.
Notes: *The first consent was obtained from the authorized representative.
** Consent was obtained (twice) from the residential participant.

The interview

Design. To gather data, a flexible approach to the semi-structured form of interviewing was employed. A semi-structured conversational style has been recommended when inquiring about information on sensitive topics (Barriball & While, 1994) from people with dementia (Tarzia et al., 2013), which it is also consistent with the IPA research method (Larkin & Thompson, 2012; Smith & Osborn, 2007). In this way, a balance was established between the information derived from participants on the one hand, and guidance that could be given to the conversation on the other.

Different researchers (Murphy et al., 2014; Smith & Osborn, 2007; Tarzia et al., 2013) provided composition suggestions for the interview schedule. For instance, the topics of the questions were sequenced from least sensitive questions first, progressing to the most sensitive questions last (e.g. introduction; friendship/ companionship; love; romance; intimacy; eroticism; sexuality). This was done to make participants more comfortable speaking with the interviewer during the interview and to become more experienced with this study. Participants seemed to feel comfortable speaking about their current experiences in intimacy and sexuality after discussing their love and life history and experiences of their current life in general.

During the course of the data collection, the question schedule was altered due to experiences during interviews. Some questions did not result in relevant information at all, such as questions on romance that followed those about love. Participants tended to not understand the difference between both constructs and the interviewer found it too complex to clarify this difference during the interviews. For individual interviews, the possible exclusion of overly sensitive or difficult topics was discussed during the introduction meeting (see Figure 1.). For example, in the introduction meeting of the couple who both suffer from dementia, it was made clear that this couple never had children. It was discussed whether this was a difficult or painful topic for the couple, which would be better avoided.

Also during the interviews, some adjustments were made to the question schedule and topic list in order to enable participants to express their experiences and opinions in their own way as much as possible. These adjustments were both in terms of content and language. For example, although discussing their intimate life was not a problem, the couple of whom both of the dyad suffered from dementia did not want to discuss their current sexual lives:

"That is something we do not talk about" (couple FG)

Interviewing participants with dementia. The impairments and their variety between participants made the interviewing more challenging, than interviewing people without dementia. Various aspects tended to be important in preparation and execution of the actual interview.

First, a location where people can feel safe and comfortable is very important for interviewing (Smith & Osborn, 2007), especially when the conversation includes sensitive topics such as intimacy and sexuality (Tarzia et al., 2013) and the participant is suffering from dementia (Dewing, 2002). Interviews were held in a comfortable location within the nursing home, mostly in the bedroom of the resident. A "do not disturb" sign on the door provided prevention from interruption and the professional caregiver on duty was also informed that the interview was taking place. Interviewing the residents in their own bedroom was beneficial for another reason. In these bedrooms, residents can keep small personal furniture and belongings, such as pictures or photo albums. These could be used during the interview by both the interviewer and the resident to clarify the context of a story. For example, in one case, a male resident showed a photo album of his 50-year anniversary to the interviewer, to explain his family structure and the fact that his wife died some time after the anniversary.

Second, in this study, an experienced psychologist in dementia care (researcher TR) executed the interviews and her skills in communicating with people with dementia proved to be of importance for the quality of the data. For example, as RCF residents with dementia are not always coherent in their orientation, it is important to recognize their current or changing perceptions in time or place. In this way, a direct estimation can be made of the importance of the information provided by the resident for the current situation, and an intervention can be performed during the interview to restore the perspective in the 'here and now'. For example, in one of the couple interviews, a female resident with dementia temporarily experienced her world as if she and her husband were still in their working life:

"You work as a teacher, right?" (couple CD)

The researcher (TR) could intervene by reminding her how old she is, as her husband just provided that information. Furthermore, despite the exclusion of residents with moderate to severe communicative impairments, some participants were affected in their communicative abilities. This sometimes resulted in vague answers or answers that were difficult to understand. Based on the experience of the researcher, different strategies could be used to clarify the answers or stories participants shared. For example, when discussing the theme of love in one case, the researcher showed a picture of a deceased spouse she found on the bedside of a participant. This helped the participant to put their love story forward as she could confirm that she was talking about her husband. In addition, some participants needed more guidance through the interview. For example, one female participant tended to forget that she was in an interview situation during the interview. The researcher had to remind her of that fact several times. It was, however, important to do this as neutrally as possible, to avoid confrontation of the participant with her disability and possibly

feeling distressed or sad about that fact:

Couple FG (F is the female spouse with dementia, I is the interviewer)
F: "Who are you, if I may ask?"
I: "I am TR and I came to interview you both"
F: "Does X (the couples authorized representative) know this?"
I: "Yes, he knows, he gave me permission to contact you."
F:"Right, what do you want to know?"

This ritual was repeated several times during the interview, but because the resident showed no actual signs of distress, the interview continued. Finally, RCF residents with dementia can be distressed by an interview in general, as questions are asked. This can be ascribed to difficulties in understanding the interview situation, especially as the researcher was unfamiliar to the participants, and to general suspiciousness resulting from the dementia process (American Psychiatric Association, 2000). Recognizing and being responsive to signals of distress starting were very important during the interviews. The length of the interview depended solely on the attention and concentration abilities of the participant(s). These were between 20 minutes and one hour. If participants wished to leave, or showed in any other way that they felt uncomfortable with proceeding, the researcher would have stopped the interview immediately. This only occurred once, as a female participant became (physically) restless after 20 minutes of interviewing. In these 20 minutes, she did provide valuable information on the topics and despite the short duration of the interview, the transcript was included in the analysis. In general, during the completion of the interview and 'handing over' of the participant to the professional caregiver on duty it was very important to avoid distress as well.

The interviews were audio-recorded using a digital recording device; because of the scaring effect a video camera can have, especially on residents with dementia, we decided not to collect video-material. Before the interview started, the digital recording device was explained to the participants. Notes of non-verbal reactions (field notes) were made during and after the interview by the researcher and were included in the transcription.

In conclusion, the location of the interview, observational contact, communication skills of the interviewer/researcher, and the choice of recording device proved to be important to the course of the interviews and the information obtained therefrom.

Data analysis

Understanding the content and complexity of the personal world of the participant was the main goal of the described study. An 'interpretative relationship' with the obtained information was engaged by the interviewer (Smith & Osborn,

2007). The complete transcription, including notes and observations, were considered data for analysis. This method of analysis was chosen in order to reveal the richness of the data and to overcome possible ambiguity of the verbal reactions. The analysis procedure was further constructed in accordance with the IPA guidelines (Larkin & Thompson, 2012; Smith & Osborn, 2007).

Despite the inclusion of the observations and notes, ambiguity was still experienced in the process of analysis. As one researcher performed the interviews (TR), the critical peer reviewer (KL) sometimes missed information regarding the context and course of the interview. This complicated the analysis process in some cases, as the first researcher was the only one present in the interviews and analysis. For example, in interviews with couples where one of the dyad members was resident in the RCF, the healthy spouse sometimes provided more information and offered clarification on something the participant with dementia said. This was, however, done in a way in which the healthy spouse bent over to the interviewer and 'whispered' the information to the interviewer, to prevent the participant with dementia being confronted with the fact that they were being corrected. We did, however, feel that conducting the interview with more than one interviewer would have had great disadvantages with respect to the course of the interviews, which would have been consequential to the information obtained. Most of the important aspects in interviewing participants with dementia (described before) depended exclusively on the nature of contact between the interviewer and participant.

Through the analysis, it became manifest that participants tended to discuss the topics of intimacy and especially, sexuality in a figuratively and sometimes 'covered' way. Proverbs, sayings, and even song lyrics were used by the participants to describe their experiences and personal worlds. It was, however, not possible most of the time, to ask the participant for clarification during the interview. For example, the male participant of the couple who both live in the RCF described their sexual history as:

> *" Yes, we grew up together" (Couple FG).*

And the single male participant described his former sexual life as:

> *"Just some fooling around" (Participant A2).*

Even more implicit, was a well-known Dutch folk song that the female individual participant sang during the interview:

> "Good were those days, in which we were young and together"
> (literal translation, Participant A1).

In addition, the interviews were held in Dutch. As research reports are written in English, translation was conducted during the writing process of results section of the research paper. In addition to the valid considerations this type of translation usually has in qualitative research, due to the figurative and 'covered' statements of the residents, this was even more challenging, and required extensive consideration. Some proverbs or sayings given by the interviewees were specifically Dutch, and when translated into English, the underlying feeling or meaning that Dutch speakers would ascribe to the statement is no longer apparent. Extensive explanation of the context and the underlying feeling or meaning in the research reports is then necessary, but challenging, especially when considering the complexity of language and practical issues, such as limitations in allowed length of research reports.

Study quality

There has been debate on how to achieve a sufficient level of quality in qualitative research in general. While the quality of quantitative research derives from reliability, validity, generalizability, and objectivity (Gibson, Timlin, Curran, & Wattis, 2004), achieving quality in qualitative research is more complex. Devers (1999) composed equivalent criteria to enhance 'rigor' in qualitative research (Devers, 1999). To meet these criteria and enhance 'rigor' and thus the quality of the described study, different techniques were performed (Boeije, 2012; Devers, 1999; Mays & Pope, 2000).

First, in order to enhance the 'external validity' (Devers, 1999), a clear and extensive description of the data collection and analysis was reported during and after the study. For this study specifically, due to the important role of the researcher, this does not enable exact replicability. However, transferability was enabled (Devers, 1999).

Second, 'reflexivity' (Devers, 1999) was used to ensure attention to this aforementioned important role of the researcher. Personal characteristics of the researcher and description of the researcher-participant relationship were considered and included in research reports to enhance 'objectivity/confirmability' (Boeije, 2012; Devers, 1999). The researcher and interviewer was a 29-year-old woman. In addition to research work, she worked as a psychologist in one of the RCFs in which the study took place. However, this researcher was not clinically responsible or involved in the selected units where the recruitment for the study took place. This researcher was responsible for the recruitment process and conducted all the interviews.

Third, two critical peer reviewers (KL, PE) played the part of 'devil's advocate' (Devers, 1999) in the complete research process. They asked critical questions on research methods, design, analysis, and interpretation of the data. Consequently, this enhanced the 'dependability/reliability' in this study. In addition, a peer reviewer performed the co-coding process (KL).

However, one commonly used technique for enhancing study quality was not possible to engage with, due to the characteristics of the participants. No member checks (e.g. receiving feedback from research participants on transcripts or abstracts of interviews) were performed in this study, as we expected that participants, due to memory impairments (American Psychiatric Association, 2000), were not able to provide the researchers with a reliable answer.

Limitations, guides and recommendations for study design.

Limitations, guides and recommendations for future study design deriving from the above-described methodological considerations and reflections are presented in chronological order of study design (see also Appendix 3.)

Preparation

During the design of the study, professionals from clinical practice were closely involved. This
proved to be very beneficial in terms of the methodological and ethical considerations; the practical execution of the study and the support base for the study in practice. It also complements recommendations from prior studies (Dewing, 2002; Tarzia et al., 2013). Combining the views of experienced researchers, with those of experienced professionals from practice in the preparation phase is there for strongly recommended for future research, especially when the population under study is vulnerable.

Furthermore, putting extensive thought in every step of the process, and reporting these steps beforehand, proved to also be, beneficial. However, this should not compromise the flexibility in the execution of the study. Flexibility, such as adjusting the interview schedule, proved to be very important, especially considering the variety in participants' characteristics.
Although, both the topic list and the question schedule were exclusively composed for this study (see Appendix 1), they were not pre-tested because of the small sample size and effort to recruit these participants in the first place. In addition, pre-testing of the interview schedule was not expected to be of any added value, due to the variety within participants, and even more so, the variety in impairments and lingual possibilities of the participants. This can be considered as a limitation as it could have influenced the results.

Procedure

The introduction meeting (see figure 1.) proved to be very important to perform a person-centered recruitment, inclusion and consent procedure, which was stressed to be important before (Bentrott & Margrett, 2011; Murphy et al., 2014; Tarzia et al., 2013). A customized inclusion process in which personal characteristics

could be taken into account, helped the researcher to estimate whether the possible participant was able to participate, without the need to quantify cognitive functions and possibly cause further distress in the participant. In addition, quantification of cognitive functions, using a cognitive screening for example, was expected not to predict the actual possibilities of the resident to participate in an interview. Furthermore, the introduction meeting enabled customization of the consent process that contributed to obtaining informed consent comfortably from both the authorized representative and the residents with dementia (see figure 1).

The authorized representatives and responsible caregivers were intensively involved in the recruitment and inclusion process. These people are closely involved in the life and care of the residential participant on a daily basis. Their views and opinions were considered of great value in the decision process. However, participating residents were not involved during the first steps of recruitment and consent (see Figure 1), and exclusion from the study was still possible after the introduction meeting. This can be considered as a limitation regarding the person-centeredness of the recruitment and inclusion process. However, with this approach we prevented a situation in which the resident would agree with enrolment, but the authorized representative disagree, resulting in the resident not participating, which could lead to confusion or distress in the resident.

On interviewing people with dementia, suggestions were made in prior research (Devers, 1999; Murphy et al., 2014; Tarzia et al., 2013), which proved to be beneficial (e.g. sequencing the interview guide; a comfortable location to interview; profound skills of the interviewer). We however experienced that especially the skills of the interviewer were very important to the process and outcome of the results. To interview people with dementia, who live in an RCF, profound knowledge on dementia and skills to guide a conversation, observe and take action on vague or non-verbal signals of distress and flexibility proved upmost important. In addition, the interviewer had to combine these actions, with the data collection, which can be seen as the primary task and can be a great limitation. However, the direct contact and individual contact between interviewer and participant proved to be very beneficial to the outcome and a strength of this described study.

Data analysis and study quality

Although no video material was collected, which can be considered a limitation, field notes on a range of non-verbal outings were included in the analysis. This proved to be of great value during the data analysis, as only one researcher was present during the interviews and the non-verbal information was at least as important to provide context to the content of the interviews, as the transcriptions of verbal information. The impairment of the participants sometimes impeded providing further verbal explanation and so non-verbal information was very important. Also

information from the introduction meetings was important to provide context. Enhancing 'rigor' in qualitative research when residents with dementia are participants proved to be challenging. Balance between study quality and practicability tended to be necessary when dealing with these participants and this research topic. Although different techniques (Devers, 1999) to enhance 'rigor' were performed (see study quality), several proposed techniques were not possible, due to (memory) impairments in participants, such as performing member checks or performing triangulation (Devers, 1999).

Conclusion

The person-centered perspective was rarely represented in research on intimacy and sexuality in RCF residents with dementia (Roelofs et al., 2015). Through the described study, we aimed at including this perspective as much as possible. To achieve this, the person-centered perspective served as a base for methodological choices and design details. This necessitated a flexible, creative, out-of-the-box approach through the course of the study. Although various dilemmas, challenges, and difficulties were faced, the value of the rich and personal data that were obtained, confirmed the idea of the starting point of the study: it was worthwhile.

Different recommendations and guides for future studies are provided. We hope this will be informative and will encourage researchers to include the person-centered perspective in future research and care policy for this important theme. However, the goal to include the person-centered perspective is not exclusively reached by the choices and approaches described, but can be seen as a first step in this direction.

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Appendix 1:
Question Schedule

Topic	Questions
Introduction	Welcome. Do you have any questions in advance?
friendship/ companionship	Can you tell me what friendship or companionship means to you? Do you experience friendship in any way, lately? If so? In what way? What does that mean to you?
love	Can you tell me what love means to you? Have you been experiencing love lately? In what way? What does that mean to you?
romance	Can you tell me what romance means to you? Have you been experiencing romance lately? In what way? What does that mean to you?
intimacy	Can you tell me what intimacy means to you? Have you been experiencing (physical or non-physical) intimacy currently? Are you experiencing any barriers to experiencing intimacy? What does that mean to you?
eroticism	Can you tell me what eroticism means to you? Have you been experiencing eroticism lately? May I ask you in what way you have experienced eroticism lately? What does that mean to you? Is it important to you?
sexuality	May I ask if you have been experiencing sexual contact lately? Are you experiencing any barriers to experiencing sexual contact? And in what way? What does that experience mean to you?
Closing	Do you even discuss any needs in intimacy or sexuality with anyone? (e.g., partner, children, responsible caregiver, psychologist, doctor) What do you think of the way the unit/caregivers handle issues in this area? Do you have any more needs in your experience in these areas? Is there, for example a proper place to experience intimacy the way you prefer? Do you still have any questions or comments? Thank for participation

Appendix 2:
Information Letter

INFORMATION LETTER

Dear Sir/Madam,
We send you this letter, because we want to kindly ask you to participate in a study.
The study is titled: "Intimacy and Sexuality in the Nursing home."
We are researchers of Tilburg University.
Tineke Roelofs will conduct the study within (Name of the RCF organization).
She works as a researcher, and also as a psychologist and is experienced in talking about private matters with people with dementia.
You decide for yourself if you want to cooperate. Before you decide, it is important to know more about the study. We therefor ask you to (calmly) read this letter.

What is this study about?
The study concerns the importance of intimacy and sexuality in people's lives.
And in this study, especially on the importance for people with dementia who live in a nursing home, and their partners.
The researcher really wants to know from the people with dementia themselves, how they experience intimacy and sexuality in their current life, and if they have any further needs and wishes in this area.

Why is this study important?
Intimacy and sexuality are important aspects of life. When people get older, suffer from dementia, or move to a nursing home, this can be of great influence on their experience of intimacy and sexuality.
This is, however, never studied before.
Through the information derived from the study, we hope to inform practice on experiences, needs and opinions of people with dementia themselves.
Participation in the study will not lead to actual changes in your current situation. However, in the long-term, we can use the results to improve the quality of care and to adapt the care process to the experiences of people with dementia.

How is this study conducted?
The researcher will conduct interviews with people with dementia, and if possible, with their partners. You largely decide the content of the interview yourself.
Your experiences and opinions are most important.
The researcher will, by any means, ask you about the importance of intimacy and sexuality in your life. She will also ask you questions about the possibilities to experience intimacy and sexuality within your current situation, possible barriers and

the way professional caregivers deal with this subject.
The interview will take between 20 minutes to one hour and will be audio taped.
Before we can start the interview, an introduction meeting will take place. In this conversation your partner or authorized representative, your responsible caregiver and the researcher will discuss how the interview can best be conducted.

Participation is voluntary
You decide yourself, if you want to participate in the study.
Participation is voluntary.
If you do not want to participate, you do not have to tell why.
If you want to participate, you also do not have to tell why. You will get a consent form from the researcher, for you to sign.
You can, of course, change your mind at any point and stop, also during or after the interview.

Your privacy is protected!
The audiotapes of the interview, are handled confidentially. They will only be used for this study. Your participation and everything you tell the researcher will not be shared with, for example, your responsible caregiver, your doctor or family.
We use data-coding to prevent that the interviews can be traced back to your person. Only the researcher has access to these codes.
We are obliged to save all the data for 15 years. You will consent with this procedure, if you participate in the study. If you do not want that, you cannot participate.

When will the study be conducted?
The interviews will take place between (depended on the organization).
The interview will be planned, when it suits your agenda.
When you have any remaining questions, you can always contact the researcher: Tineke Roelofs (contact details see below)

What happens when the study is done?
When all the interviews are conducted, the researchers will write scientific reports about them. Naturally, your name will not be mentioned in these reports.
If you are interested in these (English) reports, it is of course possible to receive a copy.
You will always receive a newsletter in Dutch, to inform you on the results.
Finally, the results from the interviews will be included in a doctoral thesis. Also in this thesis, your name will not be mentioned.

Do you have any questions?
You can discuss the participation with anyone you want, for example your partner,

your children or other relatives.
Do you have any remaining questions, after reading this letter? You can always contact the researcher: Tineke Roelofs
You can contact here through (phone number) and (email adress).

The study is conducted by:
Tineke Roelofs (affilitions)
Under supervision of:
Prof. Dr. Katrien Luijkx, (affiliations) and prof. Dr. Petri Embregts (affiliations)
Commisioned by:
(name of the RCF organization)

Appendix 3:
Guide and recommendations for study design

Preparation	
Close involvement of clinical practice in study design, methodological and ethical considerations.	• The design details connect closely to the practice situation, which contributes to the complete procedure of the study.
Extensive thought and consideration in design and methodology.	• Putting extensive thought and consideration into every step of the design and methodology contributes to successful and smooth progress of the study. • Reporting these all steps beforehand proved to be of value. This report should not compromise flexibility in the execution of the study procedure. Flexibility is important, especially considering the participant s'characteristics.
Procedure	
Investment in direct contacts with clinical practice and authorized representatives.	• Contact on management level, but especially on the level of secretary offices and professional caregivers proved to be convenient. • Where information letters can provide general information on the content and procedure of the study, during direct contact with authorized representatives, remaining questions can be answered and considerations and worries can be discussed.
The introductory meeting; inclusion and consent.	• A customized inclusion process in which personal characteristics could be taken into account helps the researcher to estimate whether the possible participant was able to participate, without the need to quantify cognitive functions. • A customized consent process contributed to obtaining informed consent comfortably and easily from the residents with dementia.

Person-centered inclusion and consent.	• In order to include residents with dementia as much as possible in the study and procedures, and facilitate the authorized representatives to do the same, the information letter was composed in such a way that the most possible participants could understand the information. Also, the two-step informed consent procedure for residential participants was performed for this reason.
Interviewing participants with dementia.	• The sequencing of interview questions from least sensitive to most sensitive proved to be effective in building up a rich, informative interview. • The skills of the interviewer proved to be very important. Experience in contact and communication with residents with dementia was necessary. • A location where the resident can feel comfortable and 'at home' tended to be very important for the course and outcome of the interview. A location set in the bedroom of the resident proved to be convenient, as personal belongings of the resident (e.g. pictures) could be used to clarify information during the interview. • The duration of the interviews should be adapted to the characteristics and impairments of the residential participants. Contact with and good observation of verbal and non-verbal signals is necessary to estimate whether the interview can continue or should be ended.
Data collection.	• The interviews were performed by one researcher, without a camera or extra observer. The interviews were audio-recorded with a small recording device and the researcher made field notes that enriched the data greatly. • A flexible approach to semi-structured interviewing helped to avoid distress in the resident and improved the outcome.

Data analysis and study quality	
Field notes.	• The inclusion of field notes in the transcriptions proved to be of great value to interpretation during data analysis. Also the information from the introductory meetings was important to provide context.
Enhancing study 'rigor'.	Enhancing 'rigor' in qualitative research when residents with dementia are participants proved challenging. Balance between study quality and practicability is necessary when dealing with these participants and this research topic.

Chapter 3 Love, intimacy and sexuality in residential dementia care: a client perspective

Under review: Roelofs, T. S. M., Luijkx, K. G., & Embregts, P. J. C. M. Love, intimacy and sexuality in residential dementia care: a client perspective.

Abstract

Background: Residential Care Facility (RCF) residents with dementia are highly dependent on care, on all life aspects. This can influence the expression and experience of intimacy and sexuality. In this study the experiences of RCF residents with dementia, and their spouses, with regard to love, intimacy and sexuality were explored.

Methods: In accordance with a qualitative research design, eight in-depth interviews were held with 12 participants; 4 couples and 4 individual residents with dementia. Method and data analysis were designed according to the IPA methodology.

Results: Varied stories were shared, with differences between couples' and individual participants' experiences. Dilemmas between loyalty, feelings of love and connectedness on the one hand, and feelings of missing, sadness and resignation on the other hand, came across. Dementia had a great impact. However, love, intimacy and being together were considered fundamentally important by both couples and individual participants. While only one couple experienced physical sexuality within the RCF, other participants reported love and being intimate connected on different levels as the most important aspect of their current relationship. Regarding the possibility of fulfilling their needs within the RCF, a sound feeling of privacy was considered to be most important, but presently absent.

Conclusion: These findings can help to address these dilemmas and normalization of intimacy and sexuality within the RCF setting and so improve the quality of life of residents with dementia and their spouses.

Introduction

When the impairments of people living with dementia are substantial and their private network is no longer able to manage the increasing care needs, an admission into a residential care facility (RCF) is inevitable. RCF residents with dementia are highly dependent on daily care and support, provided by professional caregivers, and consequently the autonomy and privacy of residents is limited. This is also true for very private aspects of their lives, such as the expression and experience of love, intimacy and sexuality. Attitudes and perspectives of caregivers can influence if and how these important aspects of life can still be expressed (Benbow & Beeston, 2012; Hajjar & Kamel, 2004).

Negative myths and stereotypical thinking surround the expression of love, intimacy and sexuality of older people. Despite these taboos, a growing number of studies demonstrate that the need for these life aspects is not confined to any age limit (Lindau et al., 2007; Weeks, 2002) and are indeed experienced as important aspect of their quality of life (QoL) (Droes et al., 2006) . For RCF residents with dementia, this taboo surrounding-or even denial of a- need for love, intimacy and sexuality is even deeper (Archibald, 1998; Everett, 2007; Roach, 2004). In a study by Archibald (1998) on attitudes of RCF managers towards sexuality, the diagnosis of dementia was found to add “another dimension”, as more conservative attitudes and concerns were reported surrounding the intimacy and sexuality of RCF residents with dementia (Archibald, 1998).

Research on the topic of intimacy and sexuality in relation to RCF residents with dementia is scarce and can be divided into different focal points (Roelofs, Luijkx, & Embregts, 2015). Firstly, intimate and sexual behaviors were observed in RCF residents with dementia. The interpretation of these reported behaviors varied from all behaviors which indicated any connection in general (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999), to exclusively sexual problem behaviors and disinhibitions (Tsatali, Tsolaki, Christodoulou, & Papaliagkas, 2010). Secondly, attitudes, perspectives, and (lack of) education of care staff were reported. Although a generally neutral to positive attitude was found, great concerns regarding how to cope with specific behaviors, and caring responsibility versus autonomy of the residents were reported (Di Napoli, Breland, & Allen, 2013; Holmes, Reingold, & Teresi, 1997). Moreover, the need for staff training and guidelines concerning resident intimacy and sexuality were underlined throughout the literature (Roelofs et al., 2015). Thirdly, theoretical perspectives and ethical considerations were described, which also concluded mainly in descriptions of dilemmas. For example, studies of legal perspectives focused on the ‘rights’ of residents versus the duty of care staff to provide a safe home (Bartlett, 2010; Everett, 2007; Kamel & Hajjar, 2004). Studies constructing theoretical frames have focused more on the (im) possibilities for expressing intimacy and sexuality, such as the need for privacy and autonomy (Everett, 2007; Mahieu & Gastmans, 2012;

Rowntree & Zufferey, 2015). Although valuable, none of these studies included the client perspective. In one qualitative study by Bauer et al. (2013) RCF residents, both with and without dementia, were interviewed on the need for and barriers to the expression of their sexuality and revealed that intimacy was still an important aspect of people's lives.

Although the client perspective is scarce in research, it is very important, as the topic of intimacy and sexuality is strongly shaped by personal factors (Bentrott & Margrett, 2011; Hajjar & Kamel, 2004). Also, with regard to clinical practice, the person-centered perspective is becoming increasingly important (Actiz, 2012a). Contributing to the Quality of Life (QoL) of residents has become a key objective for RCF's, in addition to ensuring safety and providing physical care (Actiz, 2012b; Elias & Ryan, 2011). To enable person-centered care, knowledge of the perspectives of the residents with dementia and their partners is of the utmost importance (Actiz, 2012b).

In this study, the purpose was to capture the experiences of RCF residents with dementia and their partners on their love, intimacy and sexuality. Moreover, the way people make sense of these experiences, and the factors, which impede or facilitate the possibility of experiencing intimacy and sexuality in the way these residents and couples wish, were explored.

Methods

To gather in-depth information from the client perspective, a qualitative design was chosen, according to the Interpretative Phenomenological Analysis (IPA) (Gibson, Timlin, Curran, & Wattis, 2004; Larkin & Thompson, 2012; Smith & Osborn, 2007). This design provides detailed exploration of the way in which people with dementia and their partners make sense of their own personal worlds. With this phenomenological approach, we do not aim to conclude in an objective statement that applies to residents with dementia and their partners universally. Rather, this study was a first step in understanding their meaning of experiences, needs, and beliefs, regarding love, intimacy and sexuality.

Procedure and Participants

Ethical approval was granted by the Tilburg University psychological ethics committee (reg. nr. EC-2014.27) and approval of the executive boards of the three participating organizations was obtained (Figure 1.). A detailed more description of this studies' methodology, including considerations and a guide to study design was published elsewhere (Roelofs, Luijkx, & Embregts, 2017b)

Interviews were held with RCF residents with dementia, and if possible, with their partner (couple). Participants were recruited from specialized psychogeriatric

units of three RCF organizations located in the South of the Netherlands. In these units, high intensive 24-hr nursing home care is provided. People living in these units generally have dementia in a moderate to severe stage, as living in the community was no longer possible. The participating partner could be community dwelling, or living in any form of assisted living facility.

Because RCF residents with dementia are considered legally incapacitated in the Netherlands, (informed) consent is needed from an authorized representative before enrollment in scientific research. The first enrollment for the study was therefore performed by authorized representatives, which could be the (participating) partner, children or other relatives of the resident. In some cases, a friend of the resident or legal professional served this role.

No exclusion took place based on age, sex, marital status, sexual orientation and ethnic background. In addition, no prior exclusion was performed based on etiology or severity of dementia. However, residents and/or partners with severe communicative impairments, severe attention, concentration, and frequently occurring behavioral difficulties were not included in the study (Roelofs et al., 2017b). The ability of the resident to take part in an interview was discussed and estimated during the introduction meeting with the partner or other authorized representative (proxy) of the resident and the responsible caregiver (see Figure. 1). The responsible caregiver is a member of the unit care staff who is the first contact point in care policy and procedures. During this study, no exclusion was performed based on information obtained during the introduction meeting. Also during this meeting, the most appropriate way to introduce and explain the content and procedure of the study to the resident with dementia and the adequate consent procedure, were discussed (see Figure 1.).

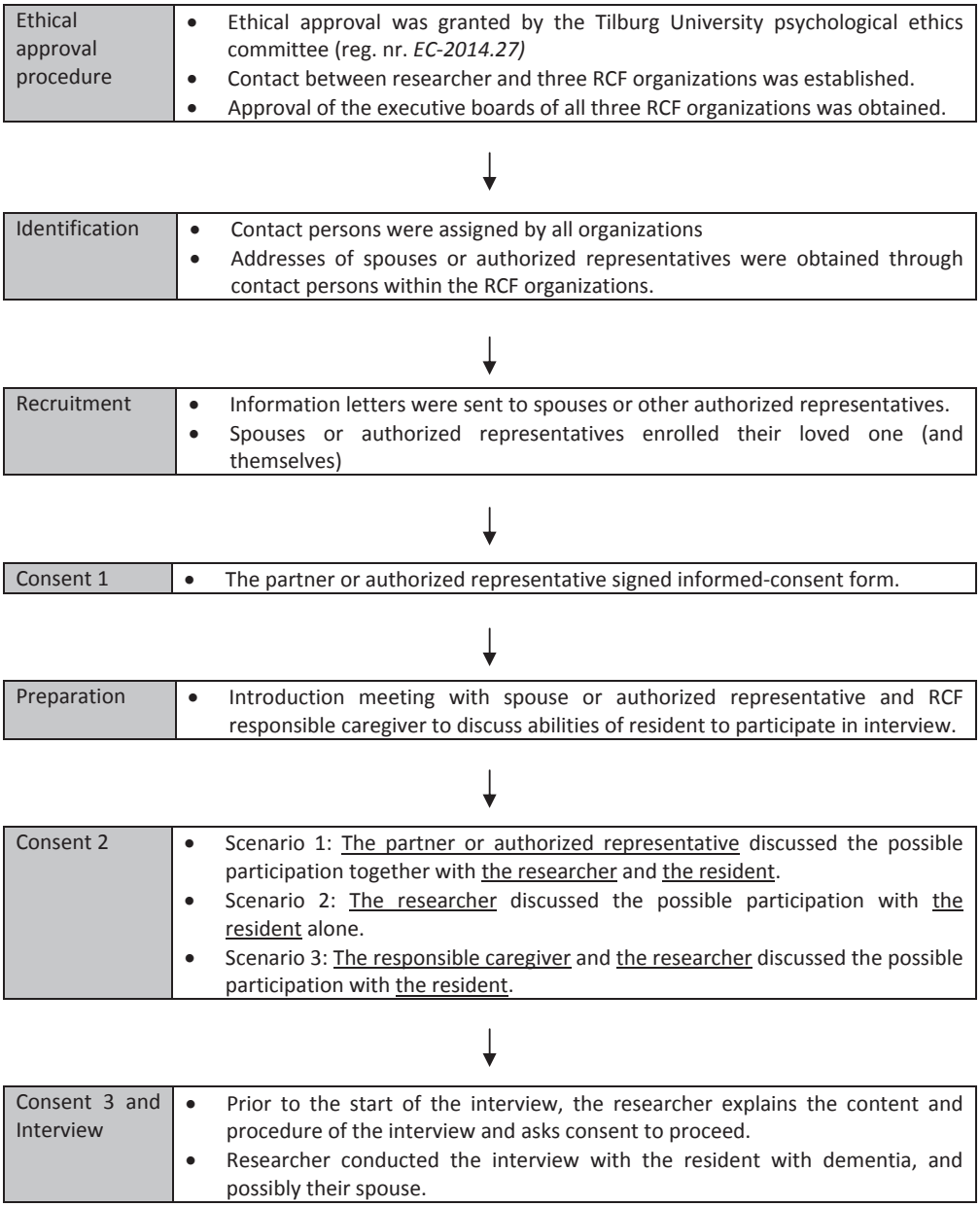

Figure 1.

Recruitment process

Data Collection and Analysis

One researcher (TR) conducted the 30-60 minute duration interviews. A suitable location was discussed and found during the introduction meeting (Roelofs et al., 2017b). The researcher (TR) works, in addition to research work, as a psychologist in one of the participating RCF's. She is experienced in communicating with people with dementia and their partners; however, she was neither clinically involved with nor responsible for any of the participating residents. The interviews were audio-recorded. The valuable (non-verbally) expressed information participants showed was also included in analyses as field notes in the transcription.

The semi-structured conversational style has been recommended when inquiring about information on sensitive topics (Barriball & While, 1994) and in conversation with residents with dementia (Tarzia, Bauer, Fetherstonhaugh, & Nay, 2013), in order to provide flexibility in the conversation. The topic list initially consisted of seven topics. During the process of data collection and analyzation, both topics 'Romance' and 'Eroticism' faded to the background, due to lack of clarity with the participants.

Table 1. Topic list

Introduction
Friendship/companionship
Love
Romance
Intimacy
Eroticism
Sexuality

A stepwise qualitative analysis was performed, conforming to the IPA guidelines (Larkin & Thompson, 2012). First, two researchers (TR, KL) performed line by line coding independently. In this coding process, the included field notes were also coded. Non-verbal expressions of emotions were identified as 'memos'. Second, discussion between the two researchers on coding resulted in one set of codes and the identified 'memos' were included in this set. The possible meaning of the statements was discussed throughout this process. Third, one author (TR) gathered all codes and identified subthemes. Following, an iterative process began in which two authors (TR, KL) discussed the meaning of statements within codes and subthemes. This concluded in a final structure of superordinate and subthemes (Table 2). Finally, in another iterative process, one author (TR) composed a narrative. Discussion amongst the authors was still present in the writing process.

To derive clinical implications that are of real benefit to clinical practice, these results were discussed during a meeting among clinical practitioners from the

RCF (staff members, professional caregivers, psychologists, care team leaders, and a member of the client board) and two of the authors (TR, KL).

Table 2. Superordinate themes and subthemes

Context
Life and love history
Current situation
Relationship and dementia: Being together
Friendship and loyalty
"Love is everything"
History of intimate and sexual lives
Intimacy and sexuality: alternative fulfillment of ongoing needs
Intimacy and sexuality in the RCF: possible, but inconvenient

Results

A (convenience) sample of 12 people participated in the study; four residents individually, and four couples (Table 3.). Although together for a long period, one couple was not married. In one of the couples, both partners lived with dementia and lived together in the RCF (couple FG). No residents who participated individually were in a relationship at the time of the interview; three were widowed and one had been single all his live. In conclusion, eight interviews were held with nine people with dementia and three healthy partners/spouses.

Table 3. Participant characteristics

	Gender of resident with dementia	Years of marriage	Relationship status
Couples			
AB	M	17	Unmarried
CD	F	unknown	Married
EF	M	50	Married
FG	M/F	48	Married
Individuals			
A1	F	-	Widow
A2	M	-	Single
A3	M	-	Widower
A4	M	-	Widower

Context

Life and Love History. Couples drew a different image from that of the single and widowed participants. The couples shared, all with smiles on their faces, the ways in which they met and how their love grew all those years ago, whereas the widowers did not mention these stories of emerging love. Couple AB described the way they met, and joked about the long years they have "*coped with each other"*. The female spouse with dementia of couple CD explained that she had always been very happy with her husband, and concluded that she must have been "*a good wife"* herself. Her healthy husband complements this by showing the photo book they have had made, from their 50-year anniversary celebration. He hands the book over and shares: "we had a great life together". The couple both living with dementia (FG) also shared their story of the way they met during commuting to their work in 1968. Since their marriage they had lived together and never had children. The wife looks back: *"That was always a very good situation"*.

The single male participant (A2) with dementia, recalled the period in which he was young and courted different girls. He never found a suitable girl to marry and now he says he is glad it turned out that way because married couples are *"always fighting"*. The two male widowers (A3, A4) both mentioned the passing of their spouse. One of them (A3) described how his wife had been ill before she died. Consistent with the rest of the interview, he did not show many emotions at all (through, for example, facial expression) and he articulated the event in an informal way and with a rural accent: *"the wife(y) was ill"*.

Current Situation. Both individual respondents and couples drew an image of their current life. In all stories, a sense of darkness, sadness and pain was displayed, related to the consequences of dementia and the living situation in the RCF. However, most participants also tried, some in vein, to play down the seriousness of their situation or share the way they currently cope with or resign themselves to it. For example, the healthy female spouse of couple EF mentioned her husband, who lives in the RCF, was crying a lot lately. If his crying gets too intense, the caregivers remove him from the shared living area and bring him to his bedroom. This causes frustration for him and he can show agitated or even aggressive behavior. To relax him, he is provided with sedative medication. The great difficulty she has with this situation was noticeable, as she told this story in a very sad way. However, she also seemed to understand the chosen interventions by explaining that other residents will start to show restlessness when her husband cries too much, so she resigns herself to it.

The male spouse with dementia of couple AB talked in detail about his current situation:

Couple AB (A is spouse with dementia, B is healthy spouse)
A: I cannot say: "There is nothing wrong with him [me], otherwise I would not be here right?"
Interviewer: Yes, that is completely true.
A: I can also feel down about it, but the one who you bother the most is yourself right? I have sometimes, when I lay in my bed that I reflect… Perhaps I reflect a little too deep about it, that I think…I know…but of course I think about it.
Interviewer: Yes, of course… And what do you think?
A: Yes, I wish things were different.

The couple (FG) both living with dementia stated that they *"quite like"* the place, but also find it a *"bit dull"*. During the interview, they seemed to change their orientation. It seemed that the wife had more orientation impairments, as she made statements that indicated she was not aware of their situation. The husband sometimes corrected her directly, and he also turned to the interviewer to correct his wife indirectly, trying not to confront her. At one point, they seem to experience the

RCF as a hotel where they stay temporarily:

> *"We are here, more or less, on a sort of… trip. We just have our own home and that is where we live together."* (Wife of couple FG).

At another point they seem to remember their 'real' situation more accurately:

> *"No, we live here [RCF]"* (Husband of couple FG).

A male widower (A3) with dementia shared that he is content in his current situation, because he gets *"food and drink on time"* and his bed is made every day. However, another male resident with dementia (A4) felt he has to *"rough it"*.

Relationship and Dementia: Being Together

Dementia was considered to have a great impact on the relationship. The healthy female spouse of couple AB puts it like:
"It [dementia] occupies a large part of our live".

She also shared that she misses her partner as a friend to come home to and to share her everyday-stories with. She feels that she can still tell her everyday-stories, but the fact that he does not remember these stories, makes her sad. She further discussed the issue of getting involved with another partner:

> *"Other people say to me, you should get another partner, and then I say, I don't need another partner! I already have a partner and that is enough for me."*

Later during the interview, she discussed/argued with her loved one on this issue. He argued that getting a new partner is *"rubbish"*, whereas she further explained that she could imagine why people say that to her. In the other interviews with couples, getting involved with another partner was not put forward.

The wish to be together was put forward by all the couples. The couple in which both spouses (FG) live with dementia put it like this:

> *"We just want to live our lives together and we don't need other people's interference."*

Two healthy spouses both shared the burden they experience because they cannot take their spouse with dementia home for a visit. One healthy male spouse even enrolled in a building project very close to the RCF, so he has a chance of gaining an apartment there. He did this, despite the uncertainty of his wife with dementia still being alive by the time the building will be finished.

One participant with dementia (A1) initially forgot she was married before. After a picture of her deceased husband was shown to her, she remembered. She continued by spontaneously starting to sing a (complete) love song by a female Dutch popular singer with the title and opening line:

"Good were those days, when we were in love and still together".

Two widowers (A3, A4) spoke about the death of their spouse. Both of their wives became unwell and died after a long illness. One of them started crying when he talked about his wife dying (A4). The other (A3) further stated that he has missed his wife very much and he has to sleep alone now.

Friendship and Loyalty

The interpretation of the concept of friendship varied between different couples. As a response to the question of what friendship means to couple CD, the male healthy spouse responded:

"We promised loyalty to each other, and we persevere with that quite good".

His (female) spouse with dementia responded to this by mentioning that they are still sweet to each other and that she still considers him as *"a friend"*. Another couple (AB) also argued they see each other as friends, and even use a Dutch loving nickname for the word friend (*"mate"*), in reference to one another.
In contrast, the couple both with dementia (FG) argued that they do not experience friendship as such. They feel love for each other, being husband and wife, which seemed in contradiction with their interpretation of friendship:

"We are really husband and wife"

"Love is everything"

Couples explained that their feeling of love for each other did not change. Couple CD shared that they are still *"very happy"* with each other and they *"put everything on the line for each other"*. In the experience of the female spouse with dementia, they still live together as a couple. Couple EF stated emphatically that love still means "everything" to them. The healthy female spouse further affirmed that "he is the only one" for her, with which she seemed to indicate that she does not feel the need to search for another (healthy) partner. Couple AB shared the experience of a changing feeling of love through time. They experience a deeper feeling of love, in contrast to the love-crush at the beginning of their relationship. As the healthy female spouse explained:

"It just slipped in, just like his disease".

She continues by explaining that the romance partly disappeared and they view each other more and more as friends instead of lovers. Finally, she revealed having protective feelings towards her spouse now:

"I don't want anything (negative) to happen to him."

To maintain their love together two couples experienced it to be necessary to put in extra effort. The healthy male spouse of couple CD explained that having many conversations was important to them as a couple. This tends to be hard now, as his wife cannot converse at the same level she used to. The male spouse with dementia of couple EF described feelings of jealousy concerning love, as his wife returns 'home' after a visit and he does not know what she does there.

One single male resident (A2) shared that he experienced love within the RCF. He had an eye on some of his female fellow residents. He doubts, however, whether the other women return his affection. The other two widowed residents both shared that they miss love. One (A3) defines it as: *"That you live happily together"*, where the other (A4) states more generally: *"Love is everything"*.

History of Intimate and Sexual Lives

Some participants shared their sexual history comprehensively; others only made some small comments. However, all contributions can be characterized by figurative, metaphorical or somewhat 'covered' language. A first example is a statement by couple FG, who did not share their sexual' lives in detail; the husband of this couple explained in this context that they: *"grew up together"*.

The healthy male spouse of couple CD described their intimate live together in more detail:

"In the old days, we could make love so well, than it was instinctive".

He further explained that their intimate and sexual life stopped after cognitive decline started with his wife and he became impotent due to physical disabilities. He colored this statement with a sense of bitter nostalgia, which was noticeable in his intonation and facial and physical expressions. Moreover, he tried to involve his wife with dementia in this part of the conversation by dividing his focus between her and the interviewer.

The single male resident with dementia (A2) supplemented his narration on his search for a suitable girl in his youth, with some figurative statements on being intimate with different girls and the way he experienced that period:

Interviewer: Did you experience love in your life?
A2: Well just some fooling around.

Another statement from him was: *"We have life and we have fun!"* (Dutch proverb), which seems to represent the youthful free spirit he experienced in this period of his live.

Intimacy and Sexuality: Alternative Fulfillment of Ongoing Needs

Various respondents said that they miss being intimate; they however put forward different reasons why intimacy or sexual activity was no longer possible. Couple CD shared that they miss sleeping together. Although they were not sexually active years before the admission, both spouses felt that not being together and not being intimate together is difficult for them. As a reason for this difficulty, the healthy male spouse of the couple said:

"Because I cannot be engaged with her as intensely anymore".

He further explained his physical problem of impotence was the start of their decreasing sexual activity. His wife, however, still felt the need for sexual activity, especially in the first stages of the dementia process. The healthy husband thought that, in those days, she probably forgot that he could not satisfy her needs.

Old age in general, was also put forward as a reason for the current absence of sexuality. Couple AB seemed to find it difficult to elaborate on this subject in detail and the healthy female spouse concluded with the statement:

"We do get older, right".

Difficulty communicating with each other on the changes in their intimate and sexual lives was shared. The healthy female spouse of couple AB said she did not want to confront her partner with dementia, so she kept her own needs to herself. Although she was the only one to make this statement openly, in the other two couple interviews where one resident with dementia was present, this mechanism of protection was clearly noticeable. The healthy male spouse of couple CD, for example, mentioned he had found it *"very hard to talk about"* with his wife, and when sharing this he lowered his voice and turned his face towards the interviewer. He did discuss the difficulties in sexuality (e.g. impotence and an ongoing sexual need in his wife) with his geriatric physician, when his wife was still living at home. He further explained, that a conversation with a Health Care Professional (HCP) on the current situation is not necessary for him. He sighs:

"You know nothing can be done".

The single and widowed respondents (A2, A3, A4) described a total absence of sexuality. Detailed reasons for this absence were not described, although one male resident (A2) expressed his position in this way:

Interviewer: "What does sexuality mean?
A2: "Nothing."
Interviewer: "Never?"
A2: "As a young boy, but not further now"

Couple EF shared they were still sexually active together, also within the RCF. Although the healthy female spouse experienced some physical problems (uterine prolapse), she and her husband found a way to be physically sexually active together, without having actual intercourse. To secure their privacy in the RCF they use a "do not disturb" sign on the door of the bedroom of her husband. This initiative was discussed with the responsible caregiver and it did not seem that they bothered about the possibility of gaining a reputation. The healthy female spouse further explained that it is sometimes difficult to feel comfortable in the RCF bedroom of her husband, because

"It is not exactly like home."

Intimacy and Sexuality in the RCF: Possible, but Inconvenient

Couple FG both of whom live with dementia shared that they sleep in two single beds, which are put together in the same bedroom. A double bed would not fit in their bedroom, the male spouse argued. They share two (RCF) rooms, one bedroom and a living room. They did not describe any barriers to expressing intimacy in their current situation.

The other couples shared diverse experiences. The healthy female spouse of couple AB said that she thought it was possible for her to stay the night in the RCF with her partner. She never did, however. Moreover, she did not experience any inconvenience or lack of privacy when she and her partner want to be together in private and she shared that communicating with the caregivers is important in order to fulfill their privacy needs:

"You just have to tell the caregivers you want to be alone and lock the door".

Couple EF, who were sexually active in the RCF, discussed the absence of a feeling of privacy and the single bed of the husband as barriers to being intimate together. This absence of privacy was despite the 'do not disturb' sign they used for the bedroom. The healthy female spouse shared that she is only comfortable with taking her top off, but does not feel comfortable enough to take more off, because she misses the 'homely' feeling in the RCF. She did mention her participation in the study as a way to

improve the possibilities for other couples to express intimacy and sexuality.
The healthy male spouse of couple CD also said she felt reserved with regard to being intimate together with his wife:

"I want to hug her more, but that is difficult… because of the visitors here".

The single and widowed participants did not mention any direct practical barriers regarding their expression of intimacy or sexuality.

Discussion

Through this study, experiences and needs of RCF residents with dementia and their spouses, with regard to love, intimacy, and sexuality, were explored. The participants shared very diverse stories on their life and love history, their current situation, and the impact this situation has on their relationship and intimate and sexual lives. In general, a sense of great loyalty, love, desire to be together and connectedness characterized the stories. However, also a "dark" sense of sadness, shamefulness, missing an intimate connection and a sense of resignation came through. These mixed emotions, which can be considered as personal dilemmas, were mentioned before in the literature (Roelofs et al., 2015), although not in this client perspective.

There were differences between the stories of the couples, and those of the individual participants. For example, with regard to their past, the couples put forward the positive, experiences of meeting each other and falling in love, whereas the individual respondents with dementia tended to share more recent, but negative stories, such as the loss of their loved one. Moreover, they shared their experiences on a more abstract level, than the couples did; two widowers with dementia shared missing their spouse and the experience of sleeping alone, which seemed to be a reference to being alone or lonely.

All participants were clear on the great importance of love and connectedness in their lives, which is consistent with findings from previous studies on important aspects of life (Bauer et al., 2013; Droes et al., 2006). The role of friendship within the relationship was defined differently among the participants. This may cohere with the changing view on the relationship after the dementia process started with one of the partners. The deep feeling of love and the sense of protection from the healthy spouse are examples that can be of influence. This was described before, from the perspective of the spouse (Mullin, Simpson, & Froggat, 2013; Roelofs, Luijkx, & Embregts, 2017a).

The couples shared missing being intimate together. One couple beautifully explained, for example, the absence of a deeper connection within the relationship,

now their shared intimacy is gone. However, the distinction between intimacy and sexuality was not clearly made. Different physical (impotence) and non-physical (being old in general) reasons were put forward to account for the absence of sexuality. These did not seem to directly influence the possibilities for experiencing intimacy together, but were mentioned in that light.

Finally, experiences of participants regarding the ability to express intimacy and sexuality within the RCF were shared. Practical barriers that impede the possibilities for this expression as desired were described, such as a single bed. While, for most participants, communication with the professional caregivers and locking the door seemed to be sufficient to feel private for having a moment together, much more privacy seemed to be needed with regard to physical intimacy, which complements prior findings (Bauer et al., 2013). The knowledge and feeling that the RCF situation is not home, despite the efforts of the professional caregivers, was noticeable throughout.

Strengths and Limitations

A small sample size was obtained, due to several factors. Firstly, RCF residents with dementia are considered legally incapacitated in the Netherlands and therefore an authorized representative had to enroll the residents to participate, which is an understandably difficult decision. Secondly, and especially, considering the sensitivity of the topic at hand. However, the IPA guidelines, in which small samples sizes are proposed, enabled us to report new and valuable results (Larkin & Thompson, 2012).

Only RCF residents with dementia who wanted to and could participate in an interview were included in the study. This could have had an influence on the results, as a small group of the total residential population was able and willing to participate. This was, however, expected and predicted in previous publication (Tarzia et al., 2013). Furthermore, interviewing people with dementia on this subject was challenging. Although none of the conversations was aborted, the amount of valuable verbal information varied between the interviews. The amount of very valuable non-verbal and more emotional information was, however, far greater than expected.

The skills of the interviewer proved to be very important, as profound knowledge of dementia and skills to guide a conversation were needed. In this study, an experienced psychologist in dementia care (TR) performed the interviews, which was very beneficial to the outcomes (Roelofs et al., 2017b). Despite the careful selection, some residents had difficulties finding words or composing sentences during the interview.

Finally, in the interviews with couples, sometimes the healthy spouse provided more information, than the spouse with dementia. He or she also provided information to his spouse with dementia, so they could participate more in the conversation. The spouses also clarified statements of the residents with dementia, which were sometimes difficult to understand without context. This was of benefit to

the results. The observations of conversations between the couples also gave an even further insight into their current lives, relationship roles and the way they mutually cope with the limitations of the spouse with dementia.

Implications

The results from this study can be considered as a first steps in the investigation of the client perspective and raise several questions for future research and considerations for worldwide clinical policy and practice.

The personal dilemmas that were described, between great loyalty, feelings of love and connectedness, and the negative feelings of missing, sadness and resignation, seem to reflect underlying needs in the participants. Knowledge of these dilemmas can be helpful for clinical practice. An open communication, in which residents and their spouses feel these conflicting feelings can be discussed, can perhaps open the possibility for further assistance or relief regarding love, intimacy and sexuality. Educational programs for RCF staff to equip them in initiating and guiding this conversation seem to be a good first step. Also a deeper look into these dilemmas through further research is necessary to inform clinical practice in more detail regarding the possibilities for recognizing and assisting residents and their spouses in this difficult period of their lives.

The same seems true for the experiences and needs concerning intimacy and sexuality. More research into the client perspective is needed to shape this body of knowledge further. Moreover, a younger, post-war generation will enter the RCF in the upcoming years, who are expected to differ in their need to remain intimate and sexually active (Neeleman, 2012). For both current and future residents it is important that the normalization of the subjects of love, intimacy and sexuality within the RCF takes place. This seems inevitable as the first step in enhancing the possibilities for experiencing these important life aspects. Open communication on the subject, a feeling of ‘permission’ to include the subject in care needs and care plans, as well as more practical measures, such as providing double beds and enhancing (the feeling of) privacy are recommended.

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Chapter 4 Love, intimacy and sexuality in residential dementia care: a spousal perspective

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Abstract

Background. The experiences and needs of spouses of residential care facility residents with dementia, regarding friendship, love, intimacy and sexuality were explored. Understanding of how spouses make sense of their experiences was pursued.

Methods. Semi-structured interviews were held with nine spouses of people with dementia, living in high intensive 24-hour care units within RCFs.

Results. The results show that friendship, love, intimacy and sexuality were still embedded in the couples' marital lives, but all in their own way. Changing roles and a shift in purpose of the relationship recurred. Although intimacy was found to be still important in the lives of spouses, emotional and practical RCF barriers were experienced by the spouses, of which the absence of communication were most important.

Implications. Our findings on the experiences of spouses with regard to intimacy and sexuality can help RCF staff and policymakers to recognize the needs of couples and take these into account.

Introduction

An increasing number of people are diagnosed with dementia, even up to 260,000 people are estimated to live currently with dementia in the Netherlands (Alzheimer Nederland, 2015). Admission to a residential care facility (RCF) is inevitable when cognitive and physical disabilities progress and care needs exceed the possibilities of the informal care network. Such an admission leads to a general decline of quality of life (QoL) in both people with dementia (residents) (Gonzalez-Salvador et al., 2000) and their spouses (Mullin, Simpson, & Froggat, 2013); older couples, who have been together for most of their lives, are separated.

With regard to the lives of spouses, both the impact of the dementia process and the admission to an RCF of their loved one have been described. For example, a change of roles within the relationship (Harris, 2009; Mullin et al., 2013) and the gradual loss of the person with dementia, causing a severe psychological burden for the spouse, were found (Baikie, 2002; Mullin et al., 2013). Moreover, conflicting feelings between increasing responsibility on the one hand and the necessity to let their spouse with dementia go on the other, have been reported (Mullin et al., 2013).

Despite negative myths and taboos, a growing number of studies show that intimacy and sexuality remain important for the QoL of people in old age (Droes et al., 2006; Lindau et al., 2007; Rheaume & Mitty, 2008). For older people and people with dementia in particular, the broad definition of sexuality as defined by the WHO (World Health Organization, 2006) seems accurate and appropriate. Here, physical sexuality is described as a part of a wide spectrum of intimacy; intimacy and sexuality are seen as lifelong elements of being human and considered important for maintaining self-worth (Hajjar & Kamel, 2004; Swartz, Diefendorf, & McGlynn-Wright, 2014; Tsatali, Tsolaki, Christodoulou, & Papaliagkas, 2010; World Health Organization, 2006). However, a decrease in physical sexuality and sexual satisfaction were found in community-dwelling couples with one partner suffering from dementia (Davies et al., 2010; Dourado, Finamore, Barosso, Santos, & Laks, 2010; Harris, 2009). Two types of experiences were described; one experience is a decrease in physical sexuality, replaced by intimacy and closeness on other levels. A second experience is of negative feelings resulting from a total decrease in both intimate and sexual satisfaction (Harris, 2009). It is assumed that the experience of love, intimacy and sexuality is even more compromised after admission to an RCF, in comparison with what people were used to (Hajjar & Kamel, 2004; Lichtenberg, 2014).

Research regarding intimacy and sexuality in the RCF has so far focused on knowledge and attitudes of caregivers, observed intimate and sexual behavior of residents and the description of a protective care culture in RCFs (Benbow & Beeston, 2012; Hajjar & Kamel, 2004; Roelofs, Luijkx, & Embregts, 2015). Hajjar and Kamel (2004) summarized known barriers to the experience of intimacy and sexuality in RCF's. Whether these barriers are actually experienced by residents with dementia

and their spouses, is unclear. In wider terms of love, intimacy and sexuality, the experienced impact on spouses of the dementia process and admission to an RCF have not been researched before. This seems important to inform care practice and policy to possibly improve the QoL of residents with dementia and their spouses. This improvement is important, in the light of the known paradigm shift in care practice and research from a more curative care perspective to a client-centered perspective, where QoL is the main focus of care (Actiz, 2012a, 2012b; White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009).

The aim of this study was to explore the experiences and needs of spouses of nursing home residents with dementia, regarding friendship, love, intimacy and sexuality. Furthermore, we try to understand how spouses make sense of their experiences. Through this understanding we expect to contribute to both research and practice regarding the perspectives of spouses of residents with dementia on what is a mostly neglected aspect of their lives.

Methods

Study design

A qualitative research design was selected to collect and analyze perspectives of the spouses. Specifically, interpretative phenomenological analysis (IPA) (Smith & Osborn, 2007) was used to shape the study design and analysis, as this was developed to enable researchers to explore people's experiences and how they make sense of their experiences, and has been previously used in health psychology research (Brocki & Wearden, 2006; Larkin & Thompson, 2012).

Participant recruitment

Participants were recruited from specialized, intensive 24-hour nursing home care units for people with dementia, form three RCFs located in the south of the Netherlands. The intensive care is provided within closed care units, which accommodate 6 to 10 people with moderate to severe dementia. Ethical approval by the Tilburg University Ethics Committee (reg. nr. EC-2014.27) and the executive boards of the three participating organizations was obtained. No exclusion of participants took place based on legality or length of the relationship, gender or age. Participants enrolled by sending back a reply form that was attached to an information letter on the study, which was sent to their home. Initially 10 spouses enrolled, one withdrew from the study before the interview took place. All nine participants gave written informed consent. Interviews were audio-recorded and transcribed. Transcripts were anonymized and subject identification codes were used as encryption to the recordings.

Data collection

Interviews were conducted between January and October 2015 and lasted between 30–60 minutes. The interviews took place according to the preference of the respondent, either at their home (n=6), or the RCF where their spouse with dementia lived (n=3). The importance of a location where people feel safe and comfortable speaking on such sensitive topics is evident and well documented (Smith & Osborn, 2007; Tarzia, Bauer, Fetherstonhaugh, & Nay, 2013)

The first author (TR) interviewed all the participants. She is a psychologist, working in a nursing home-RCF, and experienced in conversations on sensitive topics with older adults and people with dementia.

A semi-structured conversational style was chosen as this has been recommended as a data collection strategy for using IPA (Larkin & Thompson, 2012) and for inquiring about information on sensitive topics (Barriball & While, 1994). To introduce the topics, different open questions were constructed and used (Table 1).

Table 1. Initial topic list and interview guide

Introduction	Welcome
	Do you have any questions before we start the interview?
	Can you tell me something about you and your spouse/ partner?
Friendship/companionship	Can you tell me what friendship or companionship means to you?
	Have you experienced friendship in any way, recently?
	If so, in what way?
Love	Can you tell me what love means to you?
	Have you experienced love in any way, recently?
	If so, in what way?
	What does that mean to you?
Romance	Can you tell me what romance means to you?
	Have you experienced romance in any way, recently?
	If so, in what way?
	What does that mean to you?
Intimacy	Can you tell me what intimacy means to you?
	Have you experienced (physical or non-physical) intimacy, recently?
	Are you experiencing any barriers to experiencing intimacy?
	What does intimacy mean to you?
Eroticism	Can you tell me what eroticism means to you?
	Have you experienced eroticism recently?
	May I ask you in what ways you have experienced eroticism?
	What does that mean to you? Is it important to you?

Sexuality	May I ask you if you have experienced sexuality recently? Have you come across any barriers to experiencing sexuality? And in what way? What does that mean to you?
Needs	Do you discuss any needs for intimacy or sexuality with anyone? (e.g. partner, children, responsible caregiver, psychologist, doctor) What do you think of the way the unit/caregivers handle issues in this area? Do you have any more needs in these areas? Is there, for example, a proper place to experience intimacy the way you prefer? Do you have any further questions or comments?

Data analysis

An iterative and inductive process, in accordance with the "analytic process in IPA" of collection and analysis of data was performed (Larkin & Thompson, 2012; Smith & Osborn, 2007). During data collection, discussion among all the authors influenced the initial interview guide. First, questions regarding eroticism disappeared from the list, because participants tended to find these questions unclear. Second, the topics "romance" and "love" merged into one (love) as the respondents answered similarly to the questions on both topics. Finally, the focus of the interviews broadened, as the love and relationship history was more embedded in the medical or clinical history of the respondent and partner with dementia than expected.

In line with the IPA guidelines (Larkin & Thompson, 2012), all cases were individually, close and line-by-line coded. This was performed by two authors (TR, KL) independently, using ATLAS.ti. To enhance the understanding of how spouses make sense of their experiences, emotional signals, such as crying, sarcastic statements, frustration and anger were identified and coded. Second, all codes were discussed per case, by the two authors (TR, KL), until consensus was reached. During this process, both authors also reflected on their own coding and discussed the possible meaning of the statements for the participants. Third, emergent subthemes were identified in two rounds through dialogue between these two authors. The literal and emotional codes were used to do so. Fourth, all subthemes were gathered in one file. One author (TR) developed a structure from these subthemes based on content and abstraction level, using all the codes and related transcript sections. This process was closely monitored by the one other author (KL). Finally, during another iterative process, a narrative was developed. Through analysis and writing, by clustering and renaming the subthemes, superordinate themes emerged (Table 2).

Table 2. Superordinate themes and subthemes

Superordinate themes	Subthemes
Impact of dementia	
	Dementia process
	Relationship changes
	To protect and take care of
	Loyalty
Impact of the admission	
	Acceptance of the situation
	Love
	Intimacy and sexuality
RCF	
	Lack of homeliness and privacy
	Practical barriers
	Communication
Current life of spouse	
	Missing and loneliness

Results

All spouses were married to a person with dementia who had been living for between 9 and 36 months in an RCF. The current marriage of Spouse F (Table 3.) was his second marriage. In response to the first interview question: 'Can you tell me something about you and your spouse/partner? ,'some spouses revealed their love story by telling how they met their loved one all those years ago, when they got married and described what their married life was like until the process of dementia started. With the exception of spouse B, these stories were characterized by romance, love and nostalgia. For example, spouse G narrated how he and his wife first met in their home village, fell in love and eventually married. However, spouse B shared a story of a marriage with a husband with lifelong psychiatric problems. He developed dementia, which meant an increase of problematic behavior that led to a period of physical abuse towards her. This situation eventually led to the admission of her husband to an RCF. The further elaborated analysis focuses on the experienced impact of the dementia process and the admission in a RCF on these love stories in later live.

Table 3. Participant characteristics

Spouse	Gender[a]	Living situation[b]	Years of marriage	Dementia etiology[c]
A	M	CD	51	AD
B	F	CD	58	-[d]
C	M	CD	50	MP
D	M	CD	53	AD
E	F	CD	46	MP
F	M	CD	28	AD
G	M	care	60	-[d]
H	M	CD	52	AD
I	M	CD	60	VD

Notes: [a] Gender: M=male, F= female; [b] Living situation: CD= community dwelling, care= independently living in care homes; [c] Dementia etiology: AD= Alzheimer's disease, MP= Parkinson's disease, VD= vascular dementia; [d] Unknown

Impact of dementia

Dementia process. All spouses shared the process of how their loved one became ill and the consequences this process had for their relationship and their own life. They recognized several symptoms of dementia, such as forgetfulness, disorientation or deterioration in thinking and behavior. Several spouses (A, B, D, E, F, H) indicated that they did not recognize the start of the dementia process right away. They explained that in retrospect, the impairment in cognitive functioning started far before they realized at that time. Different experiences of the process were described with regard to the course of the dementia process. Spouse E, whose husband suffered from

Parkinson's disease, described a slow, progressive process with increasing physical and cognitive disabilities. Behavioral deterioration in her husband caused difficulties between the couple, as he was not able to perform normal daily activities anymore and also developed behavioral disinhibition. In frustration she expressed:

"The way that he eats, well that is just disgusting."

In contrast, spouse I, whose wife was affected by a stroke, referred to the abrupt start of physical and cognitive disabilities.

Relationship changes. All spouses described the impact of dementia on their relationship. A role change between the spouses was much discussed. As spouse C revealed:

"The equality disappears."

Spouse F described the role change between him and his wife in a different way:

"(I see her) as a patient…Not as my spouse anymore."

He further explained that there was a moment in which he first experienced this role change. At this point he also started to fear that he was taking advantage of his wife, in terms of experiencing sexuality together. However, he was not able to specify precisely when he started to feel this, or what disabilities caused the change in view. He puts this forward as:

"She was just 'too far' by then."

The male spouses also described a practical consequence of the role change. Spouse I, for example, described how he needed to take over all the work in the house, which was first carried out by his wife.

Several spouses (A, C, D, H, I) considered friendship as an important aspect of their current relationship. Respondent I considered friendship to be a substitution for the romantic relationship there was before. The spouse with dementia was literally called a "friend" by spouses A, E and I, as a description for the different, but close bond they still experienced as a couple. Spouse E argued that friendship or companionship within a relationship is a necessity for a marriage to last in general:

"Without being friends…you won't follow through for 46 years, you know?"

However, spouses C, E and F experienced that even friendship became impossible due to the progression of dementia and specifically due to disabilities in verbal communication.

To protect and take care of. As part of the role change within the couples, spouses shared both implicit and explicit increasing feelings of protection and responsibility for the well-being of their loved one. Spouse A expressed this as follows:

"I will, as much, as much as I can, provide her with a good life, as long as I live."

With regard to the current experience of love, spouses defined love as "to care for" and "to give" (A, B, D, F). Respondents described also taking more physical care of their loved ones. Spouse F described himself initially performing manicures and pedicures for his wife and eventually helping her with all daily caring tasks, such as taking showers and toilet visits. After admission to an RCF, several spouses, such as spouse D, helped the care staff with daily care tasks:

"I just put her to bed at night, and also in the afternoon."

Several spouses expressed that they had no problem with these care tasks, whereas others, described physical and emotional strains and consequently a decline in their current experience of love, resulting from the care tasks they took on:

"I walked away for a minute, and at a certain point I returned and… He was pooping in the shower. Well, that's very hard for me." (Spouse E)

Loyalty. In spite of the difficult situation and the change in the relationship due to the dementia process and the admission to an RCF, the vows the spouses took when getting married were put forward several times as an expression of their loyalty. With regard to the possibility of becoming involved with another partner, several spouses reacted dismissively. Spouse I shared a more general dilemma in this perspective:

"Sometimes I think: How long will this take?"

He asked himself this question, as he felt that he could not go on with his life emotionally, until his wife passes away.

Spouse G shared his feelings of loyalty with regard to intimacy. He now responds positively to the expressions of intimate needs of his spouse by hugging her, as 'an act of civilization', but argues that he feels uncomfortable doing this.

Impact of admission

A repeatedly shared story concerned the period just before the person with dementia was admitted to an RCF. In this period it became clear that the capacity of their spouse and the couple's social or care network were stretched to the limit. The struggle to persevere in a 24-hour care schedule and the hesitancy and dilemma surrounding the admission to an RCF were voiced by spouses A and B as follows:

> *"…I did not think I would miss her so much…because, yes, all those problems, she was aggressive all day… and… In those times (living at home) I said to myself: I will be glad when she is gone…"*

> *"..Yes.. The final period that he was still at home…yes, I am sorry, I hated that man. (…) But not anymore, you know!"*

Acceptance of the situation. Spouses described various processes of working towards acceptance of the situation. Through emotional statements (i.e. crying, anger, frustration) they drew an image of the difficulties they faced in coping with the dementia process and the inevitable admission to an RCF (A, D, E, F, H). Spouses A and H found it very hard to describe these feelings. Spouse H started crying at the start of the interview, and stated that he had a very hard time leaving his wife at the RCF in the evening.

> *"It is very hard, one to cope with, and two, to describe what happened to me."* (Spouse A)

Spouse H also described the difficulty his wife has in coping with her current situation:

> *"She hopes she will be dead by tomorrow."*

More implicitly, spouses shared a tendency to gradually say goodbye to their loved one and their life together throughout the dementia process and after the admission. Spouse F puts it as follows:

> *"It is a really slow process, with ups and downs."*

He described how he started saying goodbye to his wife at the very moment the diagnosis of Alzheimer's disease became known. Spouse B experienced the process as if her husband is dying gradually, as the dementia process worsened:

> *"He is actually dying, little by little."*

In contrast, spouse I described the process of the admission as a quick and abrupt process that forced him to say goodbye to their life together very quickly.

Some spouses also shared words of acceptance regarding the dementia process and the admission of their loved one to the RCF, such as spouse D:

> *"I just accepted it, well I still do."*

Relief that the spouse with dementia was not aware of his or her own situation was also expressed, such as by spouse I:

> *"Well, she doesn't know. Fortunately, I think she still does not know."*

Love. The experience of love varied among the spouses. Where some still experienced love in the current situation, other spouses reported the loss or total absence of love along the way of the dementia process. Spouses A, C, E and I indicated that love and romance are still very important in their marriage. Spouses A and C still expressed admiration for and attraction towards their loved one:

> *"The crazy thing is, she sits in…in that wheelchair… but actually I am still just as crazy about her as when she was 17 years old…"*

Other spouses described their love as 'thinking of each other' (respondent H), different intimate expressions such as 'cuddling' (respondent I) and 'holding hands' (respondent D) or descriptions of frequent visits to their loved ones in the RCF (respondent H). Spouse A even shared that he felt more love for his wife after her admission, because the difficult period at home had ended.
Through an emotional statement (frustration and crying) by spouse E, it becomes clear that she has great difficulty with the absence of romance and love in her current life:

> *"You know, my husband was always very romantic. Every birthday or anniversary he gave me a large bouquet of red roses. Now he doesn't give them anymore."*

Spouses B and G shared the current absence of experiences of love. Spouse G described the couples' current connection as follows:

> *"We are like this: Are you still alive?"*

Intimacy and sexuality. Although spouses mostly did not mention to experience a physical sexual relationship with their loved one; intimacy was reported to still be very important to most of the couples. The spouses also incorporated their impression

of the need of their loved one in their experiences. Spouses A, C, D and I mentioned that they thought that their loved ones needed intimacy. Spouse C quoted his wife expressed her wish to sleep together:

"Let's lie down together."

Other spouses mentioned that their spouses expressed their need for intimacy in a physical way:

"She comes over and hugs me and says: I am so happy with you!" (Spouse A)

"She just grabs my hand" (Spouse D)

Although they seemed to enjoy these expressions of the need for intimacy by their loved ones, spouses A, C, G and I also shared the difficulties, concerns and dilemmas they experienced in this context. First, practical barriers for being intimate were mentioned, such as a loved one being in a wheelchair, which limits both the possibility of moving close together and touching each other in any way. Second, spouses shared that they discouraged expressions of intimacy by their loved one, as they cannot fulfill their request to, for example, sleep together. This barrier led to frustration between couples, as spouse C shared that his wife did not understand why they could not sleep together and asked him:

"We still have a right to each other, don't we?"

The spouses B, F, G, and H mentioned the absence or closure of the need for and expression of sexuality. Spouse H described that their relationship had never been very physically intimate and spouse D described intimacy (and also sexuality) as something that *"…takes second place now…"*, due to the illness of his wife. Additionally, spouse I stated that his only condition for any form of physical intimacy was that his wife would initiate that contact. At the same time he was unsure about her physical abilities to have sexual intercourse.

In contrast, experiences of intimacy were also found to still be very important by spouses. Spouses A, C and I specifically shared their experience of intimacy as a way of "being together":

"To stroke her body and her hair, oh, then I notice. Yes, she quite likes that. Because then we are together." (Spouse I)

The way in which this intimacy is experienced varied. Spouse D described sitting in the bedroom with his spouse, in an old leather chair, holding hands. Spouse A said that he shared intimate moments with his wife during long walks together.

RCF

Lack of homeliness and privacy. Most spouses described the RCF as an uncomfortable place to experience love, intimacy or sexuality in the way they would like to (A, B, C, G, I). A lack of privacy was frequently mentioned as a cause for feeling unsafe and uncomfortable. Examples included the fact that every caregiver has a master key (spouses A and C), that they enter bedrooms without knocking (spouse A) and the use of cameras in the RCF (spouses A and D). Spouse C described the RCF as an *"unnatural situation,"* which was caused by a *"lack of homeliness."* He however mentioned the vain attempts of the caregivers to simulate a home-like situation by naming the shared living area a 'living room'. The fear of gaining a negative reputation with caregivers or other family members was also shared.

Spouse G felt belittled by the caregivers, because he was asked to leave the unit the moment his wife goes to bed at night. Several spouses shared the fact that they were convinced that they were prohibited from bringing their loved one back home with them for visits.

Practical barriers. The spouses mentioned several practical barriers to experiencing intimacy and sexuality, including environmental and architectural factors, such as shared bathrooms and lack of space in the bedroom to place a double bed. Opposite views were expressed concerning the creation of a separate, special room for couples to be intimate. Spouse A spontaneously suggested this as a potential solution that would allow him to experience intimacy:

> *"Just a separate room, where… those other people… don't come in..."*

Spouse C on the other hand, was worried about obtaining a negative reputation with the caregivers:

> *"Oh, they are doing 'something' over there… In room number 13."*

Communication. To improve the situation for couples within the RCF, the improvement of communication was suggested. Caregiving staff should speak more openly about intimacy and sexuality. Disappointed in his wife's caregivers, spouse A stated:

> *"They know she always asks me: I want to sleep with you... And that's why I find it important to discuss this. They are all people who studied to do this job and they must feel something too. They are people of flesh and blood. "*

Spouses also provided insights into the way they would like to communicate with care staff about intimacy and sexuality. Spouse I mentioned confidentiality as being of great importance when talking about this topic. It was mentioned multiple times that such a sensitive topic can be discussed more easily with an unknown (social) worker.

Furthermore, spouse E shared another insight. Before her retirement, she had worked in an RCF as a physical therapist. She noticed an increase in openness in the RCF regarding intimacy and sexuality in general, now as a spouse of a resident with dementia.

Current life of spouse

With respect to the meaning of the relationships after the admission of their loved ones, several spouses described their visits to the RCF. They however found it very important that their spouse with dementia still recognizes them, and saying hello and goodbye was described as important.

> *"She is very happy when I come over. She sees me when I come in."* (Spouse H)

The absence of this recognition was described as a burden: for example, spouse F explained that he felt less connected to his wife because she doesn't recognize him anymore.

Spouse A shared the daily strain put on him when leaving the RCF, as his wife becomes upset by that event. She doesn't understand the situation:

> *"I really don't like it...that I have to leave secretly, because I know she feels that."* (Spouse A)

Missing and loneliness

"I miss her VERY, VERY, much." (Spouse A)

Although desperately missing their loved one was reported by different spouses (A, B, C, D E, F, I), the detailing of this feeling was put forward in two different ways. Firstly, spouses shared missing their spouse physically in their proximity on a daily basis. Secondly, they shared their experience of missing the person who their loved one had been, before they became ill.

Spouse I said that he and his wife had spent only one night apart since their marriage, before the admission. Spouse D explained that he visited his wife frequently because he misses her:

"Yes, of course I miss her. That is why I go there (RCF)."

He mentioned *"coming home to an empty house"* and *"getting in to an empty bed"* as examples of daily life activities. He sometimes even talked to his wife, although she was no longer in the house, and further explains how he takes solace from the knowledge that she does the same in the RCF, so a caregiver told him.

And also the absence of the meaning this person had in their life was shared:

"He always was my great support and anchor in life." (Spouse B)

In this context, 'lovesickness' was also mentioned. Lack of recognition and reciprocity in contact and communication was shared as the most devastating aspect to the bond between the couples.

Spouse C shared a story of his daily life in which he admitted to becoming *"extremely jealous"* of a friend who had to discuss making appointments with his wife. The fact there was no longer a need to discuss these day-to-day matters with his spouse put a strong emotional strain on him. More spouses shared a strong emotional strain caused by missing their loved one in their daily life:

"That is the worst there is. All the rest is secondary." (Spouse D)

Discussion

A qualitative exploration was conducted on the experiences and needs of spouses of RCF residents with dementia, regarding friendship, love, intimacy and sexuality. The interviews were in-depth, rich reflections of these experiences in a difficult period of the spouses' lives. Both the impact of dementia and the admission of their loved ones were described in detail, as spouses narrated the life they had had together. Furthermore, the way in which the spouses made sense of the topics of friendship, love, intimacy and sexuality were deeply embedded in these stories, as these topics remained important parts of their married lives and cannot be seen in isolation.

Different stories were shared about the course of the illness, probably partly due to differences in the etiology. However, all spouses described a very difficult period, just before the admission of their loved ones to the RCF. Admission became inevitable, as the increasing care needs exceeded the capabilities of the spouses and their private network. This admission caused conflicting feelings of relief, anger and sadness and confirms the image that was drawn previously by Mullin et al. (2013). These conflicting feelings additionally influenced the experience of love for the spouses.

Changing roles within the relationship affected the lives of the spouses greatly. The purpose of the relationships shifted from being a married couple into a relationship in which the physical care for, and protection of, the spouse with dementia became most important. This finding is consistent with previous findings on general spousal experiences of living with a partner with dementia (Harris, 2009; Mullin et al., 2013). Spouses in the current study made sense of this change in different ways. Some tended to define their relationship as a friendship, with a decrease in or even closure of intimate and sexual lives together. Others took the opportunity to fulfill their new caring role including love and intimacy. These findings are in line with the two types of experiences, which were described by Harris (2009). On an emotional level, the role change meant losing an equal spouse. This caused feelings of frustration, loss, anger and sadness. However, the results in this study gave a closer insight into the way spouses make sense of their experiences. Feelings of loss were, for example, described on two different levels. First, the actual missing of the physical loved one with dementia in daily life. Second, the missing of the person the loved one once was and the role or meaning they had in the spouses 'life.

Love, emotional and physical intimacy were experienced as important aspects of being together as in contrast needs for merely physical sexuality were not shared. Consequently, direct physical limitations for expressing sexuality, due to age-related physical illness (e.g. erectile problems) such as mentioned in previous research, were not mentioned in this study (Baikie, 2002; Hajjar & Kamel, 2004). Feelings of admiration and attraction were still experienced. Love and togetherness

were expressed in different ways: through protection or taking care of the loved one, frequent visits to the RCF and by acts of intimacy, such as cuddling and holding hands. The feeling of being together was mainly expressed on the level of intimacy, which implies intertwinement of these two aspects.

The barriers to experiencing intimacy in the context of a RCF were shared. In addition to feelings such as a lack of privacy, an unnatural situation and a lack of homeliness, participants also pointed at practical barriers, such as a shared bathrooms and small bedroom sizes. However, professional caregivers seem to play a more important role in the possibilities of expressing and experiencing love, intimacy and sexuality of couples than previously known. First, the risk of developing a questionable reputation with the caregivers was shared. Second, communication with caregivers was considered an important aspect, regarding the improvement of the possibilities to experience intimacy and sexuality by the spouses. It is interesting to further focus on this role of caregivers in future research and its' implications for clinical practice.

Strengths and limitations

A major limitation of this study is the composition of the sample and its size. A small sample of spouses enrolled to participate in the study. This resulted in participants who were willing and not embarrassed to talk about a sensitive topic like intimacy and sexuality, which probably not applies to all spouses of residents with dementia. Given the sensitive topic, this was, however, expected and predicted in the literature (Tarzia et al., 2013). These limitations compromise the generalizability of the found results. Despite this shortcoming, the study offers a first in-depth, rich spousal (client) perspective on this neglected theme of intimacy and sexuality. Furthermore, IPA guidelines (Larkin & Thompson, 2012; Smith & Osborn, 2007) were used to design this study. This methodology was chosen, as it is well described and has been used in previous research on general spousal experiences (Brocki & Wearden, 2006; Mullin et al., 2013). IPA provided an opportunity to study the experiences of a small sample of spouses (Smith & Osborn, 2007). We feel the aim of exploring the experiences and needs of spouses of nursing home residents with dementia, regarding friendship, love, intimacy and sexuality was therefore achieved.

Research on the topics of love, intimacy and sexuality of (older) people with dementia is scarce. Specifically, the client perspective, including the experiences of spouses of residents with dementia in this area, is lacking in the international scientific literature as far as we know (Roelofs et al., 2015). This seems striking considering the importance of intimacy and sexuality for the QoL (Bouman, Arcelus, & Benbow, 2007; Weeks, 2002) and the very private nature of friendship, love, intimacy and sexuality. This study contributes to filling the knowledge gap on experiences of love, intimacy and sexuality by including spouses of residents in order to provide a more complete image.

Directions for future research and clinical implications

Through this study, we found friendship, love, intimacy and sexuality to be still embedded in the couples' marital lives, despite the great impact of the dementia process and admission, all in their own way. This indicates that the wide spectrum of intimacy, which was suggested before (Swartz et al., 2014; Tsatali et al., 2010; World Health Organization, 2006), might be the basis of future research. In addition, in line with the client-centered paradigm, it is important to include the client perspective in future research, as individual differences are great (Rheaume & Mitty, 2008).

Results from this study can help clinical RCF practice to understand more about the journey spouses have completed and the process they go through regarding the relationship with their spouse with dementia. Specifically, our findings on the experiences of spouses with regard to intimacy and sexuality in the RCF can help RCF staff and policymakers to recognize the needs of spouses. The results might also help them to adapt the care process to the needs of clients as well as their partner, for example in providing more opportunities to experience intimacy and sexuality as wanted, and to enhance communication opportunities. However, to do this, educational programs are needed for RCF staff to enhance adequate knowledge and skills, and by this optimize quality of life of people with dementia and their spouses.

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Part C Care staff perspective: quantitative study

Chapter 5. The influence of organizational factors on the attitudes of residential care staff toward the sexuality of residents with dementia

Submitted as: Roelofs, T. S. M., Luijkx, K. G., Cloin, M.C.M., & Embregts, P. J. C. M. The influence of organizational factors on the attitudes of residential care staff toward the sexuality of residents with dementia.

Abstract
Background. The attitudes of care staff toward the sexuality of residents with dementia they care for is assumed to influence the residents' expression of their sexuality in the way they want. This paper examines the effect of organizational factors, person-centered care, and the culture of the organization on the attitudes of care staff toward the sexuality of residents with dementia in residential care facilities (RCF).
Methods. Care staff in different functions at six RCF organizations (N = 187) participated. Using a survey, we gathered information on demographics and care-staff careers, attitudes toward resident sexuality, the culture of the organization, person-centered care, and knowledge of resident sexuality. Ordinary least square (OLS) hierarchical analyses were performed to analyze results.
Results. Care staff attitudes were found to be positively affected by person-centered care, and marginally positively affected by a supportive culture in the organization, Moreover, knowledge of resident sexuality positively affected care staff 'attitudes toward resident sexuality, and the presence of policy regarding resident sexuality affected them negatively .
Discussion and implications. Despite different study limitations, these results give a first insight in a broad perspective on care staff attitudes toward resident sexuality. In addition to improving knowledge of the care staff, enhancing person-centered care and a supportive culture in the organization will improve care-staff attitudes toward resident sexuality.

Background

Positive intimate and sexual experiences are found to influence health and quality of life (QoL) positively in the elderly (Bauer, McAuliffe, & Nay, 2007; World Health Organization, 2006; Zanni, Wick, & Walker, 2003). However, for people with dementia, enhancement of these positive experiences is not straightforward, especially not for those living in residential care facilities (RCF). Because residents with dementia depend greatly on the care staff in many areas, including sexuality (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005), attitudes of the care staff are expected to influence if and how residents are able to express their sexuality (Benbow & Beeston, 2012). As such, attitudes of the care staff might also be a barrier to sexual expression of residents with dementia (Hajjar & Kamel, 2004).

A small body of research exists on caregiver attitudes toward the sexuality of residents with dementia, based on the assumption that a more open or positive attitude positively influences the expression of sexuality by residents (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999). Although general neutral or positive attitudes were found among direct caregivers (Di Napoli, Breland, & Allen, 2013; Holmes, Reingold, & Teresi, 1997; Mahieu et al., 2015; Zeiss, Davies, & Tinklenber, 1996), care staff in general also expressed great and diverse concern regarding the sexuality of residents with dementia (Archibald, 2002; Holmes et al., 1997; Mayers, 1994). These concerns caused feelings of discomfort, which in turn might lead to the denial of residents' sexual needs or labeling sexual behavior as problematic (Archibald, 2002; Doll, 2013; Ehrenfeld et al., 1999; Roach, 2004; Ward et al., 2005).

Several factors at the level of the individual caregiver and their careers were reported to influence their attitudes toward resident sexuality. First, age was an influence. Older employees had more positive attitudes toward sexuality of residents with dementia than their younger colleagues (Bouman, Arcelus, & Benbow, 2007). This difference was attributed to the smaller age gap between the residents and older caregivers. Second, a higher level of education (Bouman et al., 2007; Di Napoli et al., 2013) and less religious adherence (Di Napoli et al., 2013) were found to enhance a more positive attitude. Finally, more knowledge of the sexuality of residents with dementia was associated with a more positive attitude of caregivers (Di Napoli et al., 2013). In another study, a training program on intimacy and sexuality in residents was found to increase this knowledge (Mayers & McBride, 1998). However, it is unknown if more knowledge leads to a more positive attitude toward resident sexuality, or vice versa. Possibly care staff with positive attitudes are also more willing to increase their knowledge of this topic. Throughout the literature, the absence of training programs was highlighted (Roelofs, Luijkx, & Embregts, 2015), and the importance of improving attitudes and reducing stigma directly in training programs, rather than just providing more knowledge, was emphasized (Di Napoli et al., 2013).

In addition to these individual factors and career characteristics (e.g. participation in a training program), previous literature has emphasized the importance of factors at the level of the organization (Archibald, 2002; Holmes et al., 1997; Roach, 2004). Based on a qualitative study, Roach (2004) concluded that attitudes toward resident sexuality are part of a broader perspective labeled as the "Guarding Discomfort Paradigm" (Archibald, 2002; Roach, 2004). This paradigm implies that care staff, reactively or proactively, try to avoid or decrease their own feelings of discomfort about resident sexuality. A supportive culture in the organization was proposed to have a positive influence on these feelings of discomfort and consequently on care staff attitudes toward resident sexuality. This culture of the organization can be defined as the organization's character and norms, based on a wide range of social phenomena (Scott, Mannion, Davies, & Marshall, 2003). Next, the importance of the presence of policy and guidelines with regard to resident sexuality has been emphasized throughout the literature, because they form part of the culture of the organization and reflect the importance a care organization attributes to resident sexuality (Archibald, 1998; Holmes et al., 1997; Roelofs et al., 2015).

In addition to the organizational culture, in recent years the concept of person-centered care has generally gained popularity in dementia care. In this concept, care is meant to be holistic and empowering, and should aim at increasing resident QoL (Edvardsson, Winblad, & Sandman, 2008; McCormack et al., 2010). This development requires organizations and care staff to consider the sexual needs of residents as a part of their basic human needs. Consequently, an increase in the provision of person-centered care might lead to more positive attitudes of care staff toward resident sexuality. To our knowledge, no research has examined this assumption. Moreover, in the literature on person-centered-care, sexual needs have not yet been considered.

The aim of this study is to examine in a broad perspective the attitudes of care staff toward the sexuality of residents with dementia, by examining the possible influence of organizational factors on care staff attitudes. In this study, organizational factors are operationalized as person-centered care and the culture of the organization. Next to the organizational factors, the role of individual factors, knowledge of resident sexuality, and some characteristics of care staff career (e.g. years of tenure and current function) over the possible effect on the main target variable "attitude" are included.

Design and methods

Setting and participants

The data for this study were collected at psychogeriatric care units of RCFs located in the south of the Netherlands. The RCFs participated in an academic collaborative network with the aim of connecting research and practice to elderly care. The participating RCFs varied in size between 590 and 1000 residents. An admission into a RCF becomes inevitable when the cognitive and physical impairments of patients with dementia rise to severity levels that make care at home with help of a private and formal care network impossible. In the Netherlands, this highly intensive care is provided in psychogeriatric care units. These are protected living environments, where approximately six to ten persons with moderate to severe dementia reside in a closed unit.

Employees with both direct and indirect contact with residents of such psychogeriatric care units were recruited. Direct caregivers are employees with a vocational level of education, who work together in a care team that belongs to a specific psychogeriatric unit and so provide direct daily care to residents with dementia. However, Dutch psychogeriatric care is organized in a multidisciplinary way. This means that several professionals with different expertise and tasks, and mostly higher levels of education, are indirectly involved in the care of residents (e.g. managers, therapists, such as physiotherapists, medical doctors, and psychologists). Although RCF care staff other than direct caregivers are less involved in daily care, they are mostly responsible for policy, guidelines, and treatment or care advice for the direct caregivers.

Initially, a convenience sample of 191 employees participated in the study. One minor (<18 years of age) was excluded because of considerations concerning the ethical review. Two respondents were excluded because they barely filled in the questionnaire (<10% of the questionnaire). To maximize the sample size in analyses, we included all cases for which 80% of the items on the dependent variable, attitude toward resident sexuality, were completed. This resulted in a final sample size of 187.

The participant characteristics are shown in Table 1. The sample was mostly female (*n* = 179, 95.7%). Mean age was 40.8 years (range 18–64), and they had an average of 16 years of tenure within care (range 1–43). Most of the participants completed an average vocational education and worked as direct caregivers.

Table 1. Participant characteristics.

		N (%)	*M* (*SD*)
Age (*n* = 186)*			40.8 (13.1)
Years of tenure (*n* = 185)*			16 (11.6)
Level of education *			
	Low vocational	27 (14.7)	
	Average vocational	83 (43.5)	
	High vocational	33 (17.3)	
	High	41 (18.4)	
Current function			
	Caregiver	135 (72.2)	
	Therapist	24 (12.8)	
	Other	28 (14.9)	
Employer (organization)*			
	A	28 (15.7)	
	B	40 (21.5)	
	C	19 (9.9)	
	D	44 (23)	
	E	39 (20.4)	
	F	15 (7.9)	
Sexual education*	No	155 (6.5)	
	Yes, 1	18 (9.8)	
	Yes, >1	13 (83.7)	
Policy*			
	Yes	75 (44.9)	
	No	92 (55.1)	

Note: *n does not add up to 187 in all variables because of missing data.

Procedure and measures

The Tilburg University psychological ethics committee granted ethical approval (Reg. No. EC 2015.60), and approval of the executive and ethical boards of the participating organizations was also obtained.

Hard-copy surveys were distributed after scheduled (team) meetings. A convenience sample was gathered through the selection of the meetings, in which all employers were represented. Approximately ten members of care staff attended these meetings and care staff with different functions were present during most meetings. Participation was voluntary and participants could withdraw from the study at any time. The participants received an information letter, an informed-consent form, and the survey for immediate completion. The informed consent form and anonymous questionnaires were stored separately. One author (TR) or a student assistant was present during data collection to answer all questions. The author and assistant aligned their answers in frequent discussions about the data-collection process.

The survey questionnaire was divided into five sections; one includes the main outcome measure (care staff attitudes toward resident sexuality), and four include the covariates. To estimate reliability of the measures based on the sample, we used Cronbach's alpha test for internal consistency. Values between .7 and .9 were considered acceptable (Field, 2013).

Main outcome measure: care staff attitudes toward sexuality. The Dutch version of the aging sexual knowledge and attitudes scale (ASKAS; Mahieu, Dierckx de Casterle, Van Elssen, & Gastmans, 2013; White, 1982) was used to assess care staff attitudes and knowledge of resident sexuality. The attitudes subsection was used as the main outcome measure; the knowledge subsection was used as a controlling variable (see below for details).

The attitude subsection consists of 25 items, rated in a seven-point Likert scale from 1 (totally disagree) to 7 (totally agree), it included such items as "Aged people have little interest in sexuality." Ten items were reversed after completion of data collection. An example of such an item is "Masturbation is an acceptable sexual activity for older males." Total scores were calculated ranging from 25 (most positive attitude) to 175 (least positive attitude) for analysis, as used before (Mahieu et al., 2013).

For this subsection, the developers of the scale found high internal consistency and reliability (Cronbach's $\alpha = .88$) and sufficient content validity (scale-level content validity Kappa = .91), based on the judgment of ten experts (Mahieu et al., 2013). Reliability was sufficient for our sample as well (Cronbach's $\alpha = .83$).

Main independent variables: person-centered care, and culture of the organization

Person-centered care. Person-centeredness is defined as a holistic view of residents,

and in this maintaining personhood, despite increasing cognitive and physical impairments (Edvardsson et al., 2008). The person-centered care assessment tool (P-CAT; Edvardsson, Fetherstonhaugh, Nay, & Gibson, 2010) was used for this study to assess the degree to which employees feel they provide person-centered-care (own assessment). The questionnaire was translated from English to Dutch after a forward and backward translation process (Brislin, 1970). The questionnaire consists of 13 items, rated in a five-point Likert scale ranging from 1 (disagree completely) to 5 (agree completely). Employees were asked to indicate to what extent they think these statements correspond to their own current work experiences. An example of such a statement is "Assessment of residents' needs is undertaken on a daily basis." Five items, which were formulated negatively, were reversed after completion of the data collection. Total scores were calculated ranging from 13 (low person-centeredness) to 65 (highest person-centeredness). Internal consistency was assessed to be good in the initial study (Cronbach's $\alpha = .84$). Both construct and content validity were also demonstrated to be good (Edvardsson et al., 2010). Internal consistency was also sufficient for our sample (Cronbach's $\alpha = .79$).

Culture of the organization. The FOCUS Questionnaire (van Muijen et al., 1999) was used to assess the culture of the RCF organization. This questionnaire was developed based on the competing values model (Quinn, 1988) and includes four cultural orientations: support, innovation, rules, and goal orientation. Different aspects of the culture of the organization define the four different orientations. The support orientation is characterized by cooperation, team spirit, and individual growth and is person based. The innovation orientation includes aspects such as creativity, anticipation, experimentation, and searching for new information. The rule orientation includes aspects such as respect for authority and division of work. It also emphasizes a hierarchical structure and communication. Finally, the goal orientation includes rationality, accomplishment, and accountability.

The four cultural orientations are measured from a descriptive and an evaluative perspective. The complete questionnaire consists of 54 items that are distributed over eight different variables (four orientations measured from two perspectives). The descriptive perspective measures directly observable behavior and consists of 25 items rated in a six-point scale (ranging from "never" to "always"). An example of an item is "How often is constructive criticism accepted?" The evaluative part measures the perception of employees regarding typical characteristics of the organization and consists of 29 items, rated on a six-point scale (ranging from "very" to "not at all"). An example of an item is "How typical is mutual understanding?"

Reliability (internal consistency) was assessed for the eight different variables separately (van Muijen et al., 1999). The internal consistency was reported to be sufficient for all scales except for the descriptive scale of the rule orientation, which consists of three items (Cronbach's $\alpha = .58$), and the evaluative scale of the innovation

orientation, which consists of four items (Cronbach's α = .69). Validity was assessed in the initial study by experts of the international FOCUS group (van Muijen et al., 1999). In our sample, internal consistency was sufficient for all scales except for the descriptive scale of the rule orientation, which consists of three items (Cronbach's α = .65) and the evaluative scale of the rule orientation, which consists of eight items (Cronbach's α = .39). For this reason, these scales (descriptive and evaluative scale of the rule orientation) were not included in the analysis.

Controlling variables

Knowledge of resident sexuality. The subsection of the Dutch version of the ASKAS (Mahieu et al., 2013) was also used to assess the knowledge of resident sexuality. This section consisted of 26 questions, including items such as "sexual activity in an aged person is often dangerous to their health." A correct answer was granted a score of 1, a wrong answer a score of 2, and when respondents chose the "I don't know" option, a score of 3 was given. Total scores were calculated, ranging from 26 (perfect score, most knowledge) to 78 (least knowledge), and used for analyses. Internal consistency was proven to be sufficient in the study of Mahieu et al. (2013; Cronbach's α = .80) and for our sample as well (Cronbach's α = .83).

Participant characteristics and characteristics of employees' careers. Gender (male/female), age (in years), level of education (low vocational, average vocational, high vocational, and high (higher professional level and university)), tenure within care (in years), and current function (caregiver, therapist, other) were assessed. Second, participation in training in handling resident sexuality (sexual education: "none," "one," or "more than one") was assessed. Finally, care organization (labeled as A through F) and the reported presence of policy concerning resident sexuality (yes/no) were included.

Analyses

Before data collection, a power analyses was performed to find an appropriate sample size, using the program G*power (Faul, Erdfelder, & Buchner, 2009). To reach a power level of .95, using an alpha of .05 and an effect size of .15, a minimal sample size of 166 respondents was required. As mentioned before, we included all cases that completed at least 80% of the dependent variable scale. The final sample size was 187, in contrast to a possible sample size of 168, when all cases would be excluded in which one or more items on the dependent variable were not completed.

Descriptive analyses were performed to assess participant characteristics. Means and standard deviations were assessed for continuous measures, percentages for categorical measures. More descriptive statistics were estimated to assess preliminary differences in attitudes regarding residents' sexuality between groups of

employees. T-tests were used for two categories: policy regarding sexuality within an organization (yes/no). Analysis of variances (ANOVA) was used for more than two categories: level of education, employer, function, and sexual education. Differences among continuous independent variables (age, years of tenure) were assessed using linear regression analysis.

Hierarchical OLS regression analyses were conducted to examine the effects on and the addition to the variance explained in the dependent variable: attitude toward resident sexuality. Knowledge of resident sexuality was entered in Model 1. Because of the expected interrelation between knowledge and attitude, the control variables age, level of education, and years of tenure were included in Model 2 (gender was excluded because of the overrepresentation of women). Employment (employer, one of the six organizations that were included in the study, labeled as A through F), policy regarding resident sexuality, current function, and training were included in Model 3. Finally, in the last model, our main independent variables of interest, person-centered care and the eight variables measuring organizational culture, were entered (Model 4). Dummy variables were constructed for four variables with categorical measures: level of education (average vocational is the reference category), employer (Organization B is the reference category), function (caregivers is reference category), and training (none is reference category). Values of .1, .05, and .01 on α level were used to test for significance of the p values. The .1 of p level is considered marginally significant, owing to the large number of variables in the model.

Results

Descriptive results

Descriptive analyses (see Table 2 for means (M) and standard deviations (SD)) have demonstrated that differences in attitude toward resident sexuality were found between groups of employees based on levels of education $F(3,178) = 11.36$, $p < .01$. Employees with high levels of education reported more positive attitudes than other employees; function $F(2,181) = 10.88$, $p < .01$. Therapists reported more positive attitudes than direct caregivers and other employees. Finally, attitudes were significantly influenced by the presence or absence of policy $t(165) = -3.79$, $p < .01$. Employees, who reported that policy regarding resident sexuality was not present, were found to have a more positive attitude than employees who did report that policy was present in their RCF organization. Descriptive results from analyses between care staff of different employers cannot be reported owing to inequality in group sizes. No single effects were found for age, years of tenure, and if employees received training concerning resident sexuality (sexual education).

Table 2. Significant differences in attitude scores between groups.

		Mean attitude score (SD)
Level of educationa		
	Low vocational	69.7 (15.3)
	Average vocational	64.6 (15.3)
	High vocational	55.7 (10.9)
	High*	52.3 (14.4)
Current functiona		
	Caregiver	63.4 (15.4)
	Therapist*	48.0 (11.6)
	Other	63.3 (15.7)
Policyb		
	Yes	65.9 (17.2)
	No	56.8 (13.5)

Notes: a Results found through ANOVA analyses; b Result found through a t-test
*Post Hoc Tukey HSD tests showed differences between groups.

Organizational factors

Complete results for all models of the effects on care staff attitudes toward resident sexuality are presented in Table 3. Model 1 shows that, indeed, knowledge has a positive effect on attitudes ($F(1,182)$ 24.39, $p < .01$), and this effect remains in all subsequent models (yet changes slightly in magnitude). More knowledge of resident sexuality goes together with a positive attitude toward resident sexuality. Model 2 shows that care staff with a 'high vocational level' (beta = −.22, $p < .05$ in Model 4) are found to have more positive attitudes toward resident sexuality than the 'average vocational level', the reference category. At first, the highest educated caregivers were also found to enhance more negative attitudes but this result diminishes as more variables are included. We found no effects of age on caregiver attitudes and years of tenure. In Model 3, significantly more negative attitudes were found in care staff of Employers B and F than Employer D, the reference category. This effect, however, diminished in Model 4, in which the culture of the organization and person-centered-care are included in the model. The presence of policy regarding resident sexuality (beta = .25, $p < .05$ in Model 4) was significantly and positively associated with the attitudes of care staff in Models 3 and 4.

In the final model (Model 4) 44% of the variance in attitudes toward resident sexuality was explained by all of the variables together, $F(25, 93) = 2.94$, $p < .01$. In this final model, person-centered care and the eight variables on the culture of the organization explained an additional 5% of the variance in attitudes. Person-centered care was found to significantly predict differences in attitudes (beta = −.22, $p < .05$). Employees reporting to provide more person-centered care, report more positive

attitudes with regard to resident sexuality. Of the six included variables measuring organizational culture, only the descriptive measurement of the support orientation was marginally significant in predicting differences in attitudes (beta = −.22, $p < .1$). Employees reporting more supportive behaviors, policies, and procedures reported more positive attitudes toward resident sexuality.

Table 3. Results from hierarchical OLS regression analyses

	Model 1		Model 2		Model 3		Model 4	
Predictors	SE	β	SE	β	SE	β	SE	β
	F (1,182) 24.39, R^2 (A. R^2) 0.12 (0.11)							
Knowledge	.12	.34***	0.11	0.26***	0.11	0.33***	0.16	0.26**
			F (6,171) 8.62, R2 (A. R2) 0.23 (0.20)					
Age			0.13	-0.11	.013	0.06	0.19	-0.05
Level of education								
Low vocational			3.33	0.12	3.60	0.02	4.62	-0.02
Average vocational (ref.)			-	-	-	-	-	-
High vocational			2.91	-0.21***	3.15	-0.24***	3.84	-0.22**
High			2.85	-0.26***	5.29	-0.23*	6.26	-0.20
Years of tenure			0.15	0.06	0.16	-0.08	0.21	-0.06
					F (16,143) 5.67, R^2 (A. ^{R2}) 0.39 (0.32)			

Employer				
A	3.55	0.11	4.13	0.13
B	3.16	0.22***	4.42	0.04
C	4.44	0.89	5.20	0.11
D (ref.)	-	-	-	-
E	3.62	0.14	4.63	0.17
F	4.45	0.18**	5.33	0.19
Policy	2.43	0.26***	3.09	0.25**
Function				
Caregivers (ref.)	-	-	-	-
HCP	5.65	-0.10	6.33	-0.10
Other	4.38	0.11	5.26	0.23*
Sexual education				
None (ref.)	-	-	-	-
one	3.62	-0.06	5.02	-0.05
> one	6.01	-0.06	7.69	-0.08
			F (23,95) 3.02, R^2 (A. R^2) 0.42 (0.28)	
Person-centered care			0.27	-0.23**
Org. culture [a]				
D. support			0.37	-0.22*
D. innovative			0.43	0.17
D. goal			0.45	-0.00
E. support			0.48	0.12

E. innovative	0.77	-0.01
E. goal	0.57	-0.22

Notes: *p < .1; **p < .05; *** p < .01; [a] D. = descriptive perspective and corresponding variable, E. = evaluative perspective and corresponding variable.

Discussion

To establish a broader understanding of the attitudes of the care staff toward the sexuality of residents with dementia, it is important to know more about the organizational factors (person-centered care and the culture of the organization) that might influence factors on an individual level (e.g., age, level of education, and knowledge of resident sexuality). The aim of this study was to determine the effect of two organizational factors, person-centered care and the culture of the care organization, on care staff attitudes toward the sexuality of residents with dementia that they care for.

Person-centered care was found to have a significant effect on these attitudes. Employees of care organizations, who feel they provide more person-centered care, have more positive attitudes toward the sexuality of residents. The person-centered care paradigm advocates that residents are viewed in a holistic and empowering way (Edvardsson et al., 2008; McCormack et al., 2010). The effect uncovered by the study of providing person-centered care on care staff attitudes toward resident sexuality seems logical, because sexuality is certainly a basic human need. However, residents' sexual needs were not explicitly mentioned in the literature on person-centered care. Moreover, we learned through previous literature that the sexual behavior of residents with dementia often causes feelings of discomfort and concern in care staff and, as a result, sexual needs are ignored or even perceived as problem behavior (Archibald, 2002; Doll, 2013; Ehrenfeld et al., 1999; Roach, 2004; Ward et al., 2005). Enhancing person-centered care might lead to more positive attitudes regarding resident sexuality and fewer feelings of discomfort and concern.

Regarding the culture of the organization, only the descriptive part of the support orientation, including observable supportive behavior, procedures, and policy in the organization, marginally affected care staff attitudes toward resident sexuality. Care staff that report their care organization to be observably more supportive had more positive attitudes toward the sexuality of residents with dementia. Our results are in line with the assumption made by Roach (2004), who noted the influence of the culture of an organization on care staff attitudes.

Results also demonstrated that the presence of policy had a significant impact on attitudes of care staff. When they reported the absence of a policy considering resident sexuality in their organization, they had a more positive attitude toward resident sexuality. This result is in contrast with previous research, in which the presence of policy was perceived as having a positive influence on care staff attitudes (Archibald, 1998; Holmes et al., 1997). This contradiction might be explained in that care staff, who reported more positive attitudes toward resident sexuality, set high standards for care in general and experienced the absence of or minimal policy or guidelines as insufficient.

Also contrary to previous research (Bouman et al., 2007), our sample did not show an effect of age or years of tenure. Although the samples of this previous study seems mostly comparable with our sample (e.g. gender and function distribution), there might be a cultural difference between the Dutch and British populations. Moreover, in the sample of Bouman et al. (2007), the residential care staff and the staff caring for residents without dementia are included; in our sample, the staff provides care exclusively to residents with dementia.

Finally, we found that knowledge of the sexuality of residents influenced care staff attitudes. This variable was included as a control variable in this study, although the results confirm previous research (Di Napoli et al., 2013) that the care staff's knowledge of resident sexuality influences their attitude greatly. Although this was not a main target variable, implications for clinical practice can be derived from this result.

Strengths and limitations

This study is characterized by several strengths and limitations. A first strength is that this study is, to our knowledge, the first attempt to assess the effect of organizational factors on care staff attitudes toward sexuality of residents with dementia. Although assumptions were made in previous research, an actual assessment has not yet been undertaken (Archibald, 1998; Holmes et al., 1997; Roach, 2004). Moreover, in the final analyses, we did control for individual factors that were proven to have an effect on the attitudes of care staff toward resident sexuality in previous studies (except for religious adherence). Throughout this study, a wider view and understanding of attitudes of care staff toward the sexuality of residents with dementia is provided.

A second strength lies in the data collection. The completion of the questionnaires was planned after scheduled (team) meetings. Remaining participant questions could be answered before, during, and after completion. Most questions were related to textual and lingual ambiguities; none were related to completing the knowledge question. During some team meetings, discussion arose on the topic of resident sexuality. The topic raised thoughts and concerns among care staff, as they potentially reevaluated their knowledge, attitude, and skills in responding to the sexual needs of residents with dementia.

This study also has limitations. First, the way data were collected yielded a limitation, because care staff might have felt peer pressure to participate. Although both the author and trained student assistant emphasized that participation was voluntary and withdrawal was possible at any time, the care staff still chose to participate.

Second, we encountered limitations with the questionnaires. First, the way measures are granted in the knowledge section of the ASKAS questionnaire prompted a discussion among the authors. An incorrect answer was granted a "higher" score than the "I don't know" option, which seems counterintuitive. It

means that respondents who admit to not knowing the answer are perceived as having less knowledge of resident sexuality than respondents who gave an incorrect answer. However, this questionnaire has been well studied and validated (Mahieu et al., 2013), and was used several times in this way. Therefore, we decided to use the questionnaire in the prescribed way. Second, the rule orientation, in both the descriptive and evaluative part of the FOCUS questionnaire, proved insufficient in internal consistency and, therefore, was not included in the OLS hierarchical analyses. Although this questionnaire is well studied (van Muijen et al., 1999), the number of items per scale (variable) ranged from three to eight, which is very small. Cronbach's α coefficient tends to be sensitive to only a small number of items (Field, 2013). Moreover, the outcome measures were divided over eight variables, which complicated statistical analyses. It did, however, give us a detailed look into the culture of the organization, based on a broadly used model of competing values (Quinn, 1988).

A third limitation lies in the study's rather small scale. Only one region in the Netherlands was selected, which is a limitation with regard to generalization. Moreover, in this region of the Netherlands, most residents are Christian (Catholic or Protestant), which is why we did not include religion as an individual factor (Di Napoli et al., 2013).

Finally, the gender distribution was a limitation, because women were overrepresented in the sample. A gender effect on the attitudes could not be explored owing to this distribution. However, this distribution is representative of the actual situation in clinical practice, and this was also the experience of researchers who conducted previous studies (Di Napoli et al., 2013; Ward et al., 2005).

Implications for practice and future research

Next to known benefits (Edvardsson et al., 2008; McCormack et al., 2010), the enhancement of person-centered care in dementia care can improve care staff attitudes toward many areas of life, including sexuality. Providing person-centered care will not only influence attitudes toward resident sexuality but, for example, might also decrease agitation in residents (Chenoweth et al., 2009). Moreover, improvement of a supportive culture of organization can contribute to more positive attitudes toward resident sexuality. Providing an open and supportive culture will encourage care staff to express their feelings of discomfort openly and initiate an open discussion on resident sexuality. This open discussion will probably improve the possibility for residents to express and experience sexuality in the way they want.

However, neither implication is straightforward in its practical implementation. Both imply a profound change on the organizational level, which, of course, is far more comprehensive than providing a training program on resident sexuality. It seems to be worth the effort, because greater improvements in the QoL for residents with dementia can be expected from providing both person-centered

care and a supportive culture in the care organization than can be expected from providing just a training program.

Furthermore, greater knowledge of resident sexuality was specifically found to benefit care staff attitudes toward resident sexuality. This implies that improving knowledge will improve the attitudes of care staff toward resident sexuality. The way to improve this knowledge needs more detailed consideration, because participation in education in resident sexuality did not significantly influence these attitudes in our study. In previous research, greater knowledge was found as a result of a training program (Mayers & McBride, 1998).

To further close the lacuna in research, the assumed influence of the attitude toward resident sexuality on the actual behavior of care staff needs further investigation. The behavior of care staff was found to be important, because they influence the possibility of residents and their possible partners expressing sexuality as they want. Spouses of residents mentioned, in qualitative research, that the behavior of care staff (both direct and indirect care staff) was important to their experiences of intimacy and sexuality (Roelofs, Luijkx, & Embregts, 2017). However, a clear confirmation of the influence of care staff attitudes on their actual behavior concerning resident sexuality is lacking.

Finally, replication of this study, in another cultural setting, could add detail to the image that is presented here, especially as future generations of the elderly enter RCFs, and will probably demand more facilitation with regard to their intimate and sexual needs (Neeleman, 2012).

In conclusion, we found that mainly person-centered care, as well as a supportive culture of the care organization, affects care staff attitudes regarding the sexuality of residents with dementia that they care for. It is therefore recommended to enhance person-centered care and a supportive culture in dementia care, because these aspects are expected to improve care staff's attitudes toward sexuality, as well as many other of life's domains.

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General Discussion

Although intimacy and sexuality are important throughout life (World Health Organization, 2006), expression of intimacy and sexuality by elderly people, and especially people with dementia living in nursing homes, is still surrounded by taboo and prejudices (Rheaume & Mitty, 2008). People with dementia living in nursing homes are highly dependent on others in all domains of life, including intimacy and sexuality (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005). A paradigm shift took place in these nursing homes (Actiz, 2012; Edvardsson, Winblad, & Sandman, 2008) that caused the provision of person-centered care to be increasingly important and the enhancement of Quality of life (QoL) of the resident to be more and more the focus of care. In practice, this change seems not to entail intimacy and sexuality, as the expression of intimacy and sexuality by these residents raises concerns and is considered a complex issue (Archibald, 1998).

Research on the topic of intimacy and sexuality among nursing home residents with dementia is scarce, and the present thesis aims to contribute to the research field and clinical practice alike. This doctoral thesis placed equal emphasis on research and practice. The theme of the research was derived from issues encountered in daily care practice. Research questions, study design, study execution and interpretation of the results were all designed and executed in close collaboration between research and care practice.

The overall aim of this doctoral thesis was to improve understanding of normal or healthy intimacy and sexuality in nursing home residents with dementia and their partners from the client perspective as well as the care staff perspective. Through the provision of insights and consequently understanding, we hope to improve the quality of care and consequently the quality of life of nursing homes residents with dementia and their partners. In line with the close collaboration between research and practice, and consistent with the aforementioned paradigm shift, a practice based and person-centered research question was composed.

> In what way can nursing home residents, and possibly their partners, be best supported in their wishes and needs with regard to intimacy and sexuality?

To explore intimacy and sexuality in residents with dementia we chose to explore different perspectives through different designs. First, a review of previously published empirical studies was conducted. Secondly, a qualitative study involving interviews with nursing home residents with dementia and their spouses was conducted. Finally, a survey of care staff was administered to examine the influence of organizational factors on the care staff's perspectives regarding resident sexuality. The thesis is divided accordingly into three sections, Parts A, B and C. In this general discussion, a summary and interpretation of the main findings is presented. Also,

strengths and limitations of the study and implications for future research and clinical practice are described. In this final section, also the main research question is answered.

Summary and interpretation of main findings

Part A. Literature

A systematic literature review was performed in order to obtain an overview of the (recent) empirical research on the intimacy and sexuality of nursing home residents with dementia. Twelve papers concerning "normal" or "healthy" intimacy and sexuality were included. As only empirical research was included, the publications on theoretical perspectives and legal and ethical dilemmas and considerations, which are discussed in the general introduction of this thesis, were excluded. Consequently, papers could be divided in two focuses: reports of behavior of residents and knowledge and attitude of care staff of residential care facilities (RCF's). Most important results are in the context of these outcome measures: behavior was mostly observed and reported by proxy and ranged from "touching hands," to "masturbation" (de Medeiros, Rosenberg, Baker, & Onyike, 2008; Doll, 2013; Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999; Tzeng, Lin, Shyr, & Wen, 2009). Attitudes and knowledge of caregivers were found to be generally neutral, but dementia added "another dimension" (Archibald, 1998). A variety of individual variables were found to influence caregiver attitudes, such as age and educational level (Di Napoli, Breland, & Allen, 2013; Holmes, Reingold, & Teresi, 1997; Ward et al., 2005). Next to these outcomes, gender was found to be a major issue, as male caregivers tended to pursue sexuality of female residents as more problematic and female caregivers vice versa (Ward et al., 2005), although it was never reported as a main result of a study. Finally, a dilemma concerning capacity to consent in intimate and sexual behavior was reported in several publications on attitudes of care staff (Archibald, 2002; Di Napoli et al., 2013; Holmes et al., 1997). A major conclusion from this review was the lack of attention to the client's perspective. This perspective was, at the time, not represented in research at all. We found this remarkable, as intimacy and sexuality are very personal and even private topics. During the execution of the empirical phase of the current research, and after publishing our review, one study was published that included the client perspective of residents of different residential care facilities on intimacy and sexuality (Bauer et al., 2013). Bauer et al. found that sexuality still mattered for these residents, although their preferences and needs for expression of sexuality varied. Moreover, different barriers to sexual expression were described. In this study, residents with and without dementia were interviewed and analyses were performed on data of both groups together. Furthermore, these residents lived in high care, low care and mixed care situations.

Part B. The client perspective on intimacy and sexuality

A main conclusion of the literature review presented in Part A was the lack of the client perspective in research so far. This was a surprising finding, when considering the private nature of the subject of intimacy and sexuality. Moreover, this was even more surprising given that the person-centered care paradigm is increasingly important in RCF care practice and research. In this approach, the resident is perceived in a holistic way, including all aspects of life and shared decision making (Edvardsson et al., 2008). In contrast with the participants in Bauer's (2013) study discussed in the previous paragraph, the participants in our qualitative study lived in high care, closed, psychogeriatric units or are the spouse of a person living here. This care setting not only influences the possibilities for expression of intimacy and sexuality greatly, it is also an indicator of the level of cognitive functioning of the participants with dementia. The included people with dementia were all highly dependent on intensive care in many domains of their life. The inclusion of that client perspective on their experience of intimacy and sexuality and the way they make sense of these experiences was the aim of the study presented in section B (Chapter Three and Four) of this thesis. Seventeen interviews were conducted in total; four with couples together, four individual interviews with a resident with dementia and nine with spouses of a resident with dementia. Analysis and report of the data was divided in two papers based on the source of the data; Chapter three concerns results derived from individual interviews with residents with dementia and couples; Chapter four concerns results derived from interviews with spouses of residents with dementia. All interviews yielded rich data, and after analyses different focal points were identified. The most important are reported in the following section.

The changed relationship through the dementia process: Mixed emotions. Through study B presented in chapter three and four, dementia was found to greatly influence the relationship of the respondents from the very start of the illness. Although the course of the illness was described variously, probably due to differences in etiology of dementia, the outcome was rather similar. Relationships changed dramatically because of the increasing impairments the process of dementia caused and, subsequently, the increasing care need. Eventually, the care that the person with dementia needed exceeded what the private care network could provide, even in cooperation with formal care. This admission means that couples were separated, often after very long periods of being together. In our study presented in part B (Chapter four), spouses of residents with dementia drew an image of a relationship that slowly changed and for most spouses not for the better. Although some individuals took their new role as a caregiver and protector positively, most spouses experienced the decline of their loved ones' cognitive and physical abilities as a large burden on their whole life. In a study by Mullin, Simpson, and Froggat (2013), which focused on relationship changes occurring when one of the partners develops

dementia and is placed in a nursing home while the healthy partner continued to be community dwelling, the changed role within the relationship from an equal spouse into the role of caretaker or protector was described to be destructive for the relationship. In our study, spouses described mixed emotions, as they slowly lost their partner, without actually losing them, causing a feeling that there is no closure. Feelings of responsibility, friendship and love intertwined with feelings of frustration and sadness. In the study by Mullin, Simpson, and Froggat (2013), these feelings were also described in detail and even defined as a loss of identity. The actual admission to a nursing home of the partner with dementia caused mixed emotions in spouses of our study, including relief because of the ending of a difficult caregiving situation on the one hand, and an even greater sense of loss and a sense of failure on the other hand.

Love and Intimacy are most important: being together. Not only couples and spouses, but also single respondents, pointed out that love was still a very important aspect of their life even after admission to a nursing home. Although the scope of the thesis and qualitative study (part B) was initially limited to the topics of intimacy and sexuality, through the interviews, it became clear that these subjects couldn't be separated from the concept of love. We found that both residents with dementia and their spouses made sense of the topics of intimacy and sexuality as embedded parts of their love and life history and present. Physical and emotional intimacies were defined as important aspects of "being together" and an absence of this intimacy as missing of a deeper connection. This deeper connection and the sense of being together were shaped in very diverse ways. People described taking long walks together, holding hands, sitting close to each other or just being together in the same room. Acts of protection and taking care of the partner with dementia were also described as an aspect of "being together." As an attempt to be together with his wife as much as possible, one husband reported purchasing an apartment in a building under construction next to the nursing home. There was a chance that this building would not be finished before his wife passed away, but that was a risk he was willing to take.

On the negative side, missing being together and loss of love and intimacy were important issues for many couples. These feelings were strongly consistent with the negative feelings described with regard to the changed relationship. As mentioned before, living with a spouse with dementia means losing that person bit by bit, without the possibility for closure. This dilemma between sadness and frustration over the loss and the feeling that "you need to be glad to still have" the partner and the feelings of responsibility for protecting the partner caused great burden for spouses. Participants were not afraid to share emotional statements of frustration and sadness, which were imaginable and confronting.

When looking at these results in light of previous literature, two types of experiences ("less sexuality but more intimacy" and "limited intimacy on multiple levels") with regard to intimacy of community dwelling couples where one member of the dyads had early stage dementia were described both in a study by Harris (2009) and in our own data. Moreover, our results are a clear confirmation of the result found in a study on experienced Quality of Life (QoL) where intimacy was reported to be an important factor in their QoL by people with dementia who were both community dwelling and living in a nursing home (Droes et al., 2006). However, in our study, residents with dementia (Chapter three) and their spouses (Chapter three and four) described positive and negative experiences as closely intertwined, which consequently caused mixed emotions and dilemmas. This emotional aspect of participants' experiences is one of the main results of this study and seems very central to the experience of people in this situation and the way they make sense of this experience.

Intimacy and sexuality: Still important although difficult and different. Sexuality was often described in stories on the love and life history of the residents and their spouses. Although intimacy, both physical and emotional, were recognized to be very important, physical sexuality was not accorded the same importance in the participants' current situation, as was the case before. Only one couple revealed being currently sexually active together within the nursing home. They described their sexual activity as being very important (Part B, chapter three).

In general, the distinction between (physical) intimacy and sexuality was often not defined clearly, which confirms the assumption that intimacy and sexuality should be defined broadly, especially for nursing home residents with dementia (Hajjar & Kamel, 2004). Moreover, the physical descriptions of sexuality were sometimes put forward in disguised terms or metaphorically. This indicates that the subject is still taboo, even though the residents and their spouses who enrolled and took part in this qualitative study (part B) seemed to be quite open-minded. General perceptions of old-age sexuality and generational effects (see introduction for details) seem to influence the prejudices. This observation is, however, most important for clinical practice, as it indicates that interventions or even a conversation on sexuality should be initiated by the care staff.

As in previous research, absence of physical sexuality was attributed to physical (biological), psychological and social factors (see introduction for details). Physical problems were mentioned, for example impotence in male participants, as a reason for a complete cessation of the sex lives of couples. However, both psychological and social factors were more often described compared to physical factors, as having an (negative) impact on the sex lives of residents and their partners.

With regard to psychological factors, the mixed emotions and dilemma caused by the changed relationship appeared to have an impact on the sex lives of residents with dementia and their spouses. Individual experiences of balancing between feelings of comfort and discomfort shaped the core of the psychological factors. All of the spouses and couples were searching for a balance between the comforting feeling of being intimate in the way they were used to and feelings of discomfort caused by the changing roles within the relationship, in their own way. In some cases, this search felt like a lonely one, because the partner with dementia was severely impaired or did not show any needs on the intimate or sexual level. For others, the struggle appeared to be more painful, as their partner with dementia clearly showed the need for intimacy or openly requested sleeping together. This was not always possible due to barriers raised by the nursing home, but mostly, the spouse struggled with their own feelings of discomfort arising from a (potential) physical sexual relationship with their demented spouse. Different spouses described this discomfort as a feeling of protection, as they do not want to harm their spouse in any way. Also being scared of abusing or taking advantage of their partner was mentioned. However, also, feelings of frustration, anger, sadness, and loss, and feelings of disgust towards their loved one with dementia, were expressed; most spouses did not know what to do with such feelings. Ultimately, participants who described these feelings did not seem to discuss them with anyone else, perhaps because of feelings of shame induced by the earlier mentioned taboo or feelings of shame of their feelings toward their demented spouse.

Social factors were more present in individual or single participants (Part B, chapter three). For example, three of them were widowed, which left them alone and not in a position or wanting to look for another partner. For single people, as for couples, admission into a nursing home means giving up their privacy. In the study by (Bauer et al., 2013), this was more explicitly mentioned as a result, probably due to the greater cognitive abilities of the single participants. Barriers within the nursing home were asked about explicitly during the interviews, and therefore were most represented (see the following paragraph for details).

Barriers to expression of intimacy and sexuality in the nursing home

Our respondents mentioned many barriers to expression of intimacy and sexuality, which set light on a very different perspective with regard to these barriers compared to barriers described in previous research. First, practical barriers were mentioned. Examples included the use of single beds and the impossibility of placing a double bed in the small nursing home room. Also, the (necessary) use of large wheelchairs was mentioned. Second, emotional barriers and the lack of privacy were noted. Respondents reflected on their experiences in the nursing home and some concluded that this nursing home situation would never “feel like home.” The couple that said they were sexually active together within the nursing home mentioned lack

of privacy as a barrier, as the female healthy spouse said that she never undressed herself completely because of this. Although the effort of the care staff to establish it was recognized by all participants, the homey feeling that is needed to experience sexuality within the nursing home seems difficult to recreate. Locking the door, the use of a "do not disturb" sign and communicating with care staff about the needs of residents were mentioned as steps that could be taken to create such an atmosphere. However, care staff tends to use a master key, for security reasons. A "do not disturb" sign causes the need for that sign to be overt, which impedes privacy.

Finally, barriers concerning communication with the care staff were mentioned. When looking in more detail at the descriptions of these barriers, spouses of residents with dementia reflect on the lack of initiative and skills of care staff to discuss the topic seriously.

In previous research, Hajjar and Kamel (2004) defined barriers to the experience of sexuality in the nursing home based on a literature review. A comparison between these barriers and the barriers we found through our interviews gives some insight into the differences these different perspectives can bring forward (see Box 1). Whereas the barriers derived from Hajjar and Kamel's (2004) study tend to be on an abstract or theoretical level, the examples put forward by residents with dementia and their partners in our study were defined on a more detailed and practical level. For example, the barrier defined as "attitudes of staff" in the study of Hajjar and Kamel (2004) is similar to far more detailed and specific descriptions given in our study that we categorized as "communication barriers." The same is true for "lack of privacy," described as an important barrier in their study. Our study suggested that barriers to privacy were not as straightforward as the term might suggest, as the efforts of care staff to provide privacy were recognized and appreciated by residents and their spouses, but were not sufficient to provide a homey feeling and provide sufficient feelings of privacy to express intimacy and sexuality comfortably. We hope that such details will provide concrete insights that can inform practice, which was the main goal of this study and the direction of the main research question. Moreover, results on this level will hopefully also enhance the impact of clients' perspective in scientific research.

Barriers from empirical study in Part B	Barriers from literature review (Hajjar & Kamel, 2004)
• Practical Barriers *Single beds* *Shared bathrooms* *Small bedrooms* • Emotional Barriers and lack of privacy *No homey feeling* *No feeling of privacy* • Communication Barriers *No initiative in communication by the care staff* *Confidentiality is very important*	• Lack of privacy • Lack of a willing partner • Mental Illness • Physical limitations • Attitudes of staff • Attitudes of family members • Adverse effects of medications • Feelings of being unattractive • Erectile dysfunction in men • Dyspareunia in women

Box 1. Comparison between barriers derived from our empirical study presented in Part B and from literature (Hajjar & Kamel, 2004) .

Including the client perspective: Methodological considerations

The perspectives of nursing home residents with dementia and their spouses were included in chapter three and four, presented in Part B. Although very rich data were gathered and the results contributed to closing a gap in the research field, the design and execution of the study were not straightforward. Different challenges and difficulties were encountered during the process of design and execution of the empirical study among residents with dementia and their spouses, presented in Part B. Throughout the course of the study, we learned a lot about the process of performing qualitative research on residents with dementia, and were able to share these experiences in a methodological paper (Chapter Two).

Preparation. We chose to design the study in close collaboration between research and practice (see preface for details), which contributed to the practicality of the study. The chosen methodology enables us to explore the experiences of the participants and make sense of these experiences. The Interpretative Phenomenological Analysis (IPA) described by (Larkin & Thompson, 2012; Smith & Osborn, 2007) was chosen as a design and analysis methodology, as this was well described and previously used (Brocki & Wearden, 2006). Ethical considerations both on the participant and methodology level were extensively discussed in the preparation phase. For example, we discussed issues such as the following: What should a recruitment or consent procedure consist of? What is important when we want to include the resident with dementia as much as possible in the decision making process? How can we, in an ethically responsible manner, retrieve as much valuable information as possible?

In this preparation phase we made a lot of decisions based on these questions. One of these decisions was to not assess the cognitive abilities of the participating residents with dementia with the aim of excluding participants based on those assessments. This decision had pros and cons. The authorized representatives of the potential participants evaluated the abilities of their loved ones to competently participate in an interview. The information gathered in all the interviews was very rich and valuable. However, from a replicability perspective this was a limitation (see the limitation section for more information) as, especially in international perspective, cognitive ability is not easy to estimate purely based on a description of the level of dependency and care provided.

Procedure. To ensure successful execution of the study, a fair amount of time was invested in contact with clinical staff and the authorized representatives, to provide access to the potential participants and help the data collection process proceed smoothly. In Figure 1 of Chapter Two, the recruitment and consent procedure are presented. Both were custom made for the group of residents with dementia. However, in line with the shared-decision making concept of the person-centered care paradigm (Edvardsson et al., 2008; McCormack et al., 2010), and more specifically according to Dewing (2002), all participants, including those with dementia, were involved in the "ritual" of informed consent, and this was therefore designed as is normally the case, as much as possible (Dewing, 2002).

The execution of the interviews with people with dementia and their spouses demanded special attention. Based on suggestions of researchers who have previously described the methodology of interviewing people with dementia (Murphy, Jordan, Hunter, Cooney, & Casey, 2014; Smith & Osborn, 2007; Tarzia, Bauer, Fetherstonhaugh, & Nay, 2013), a topic list and interview schedule were constructed starting with the least sensitive topics and ascending to the most sensitive topics. To end the interview well, and lighten up the conversation at the end, practical questions were asked last. Creating a comfortable atmosphere and conducting the interview, as a comfortable conversation was important to increase the information gathered. To do so, experience in conversation with people with dementia was crucial. As suggested by others (Tarzia et al., 2013), a combination of flexibility in conversation and leading the conversation were important for gathering the information.

Analysis. To put the verbal results of the interviews in the right perspective, field notes of non-verbal signs proved to be very important. Examples of these outings are physical outings, but also non-verbal interactions between couples, for example. As the IPA method prescribes, all interviews were analyzed individually, as if they were case studies (Larkin & Thompson, 2012; Smith & Osborn, 2007). This enabled us to assess the interviews very closely and interpret the way residents and their partners made sense of their experiences on an individual level. Although we aimed to perform

the analysis on these data as well as possible, different limitations with regard to rigor and study quality characterize this analysis process. These are discussed further in the strengths and limitations section. However, we found very valuable, rich information to inform both research and practice and consider this study as a first step to try to include the perspective of nursing home residents in scientific research that in turn will hopefully lead to more understanding of the way this group of people make sense of their experiences.

In conclusion: a person-centered view on a complex theme

When reviewing the results gathered through the empirical qualitative study as well as the methodological considerations and experiences presented in Part B, several major conclusions that transcend the aforementioned themes can be drawn.

First, we found out that for residents with dementia and their spouses, intimacy and sexuality were not concepts that existed in isolation; these concepts were deeply embedded in the former and current love lives of residents with dementia and their spouses. In the design phase of the study, and during the composition of the literature review, we assumed that these concepts could be studied separately, as was done before.

Second, in literature, the presence of taboos and prejudices is mentioned throughout. Also during the recruitment process for this empirical study, we encountered taboos among authorized representatives, especially when these representatives were children of the possible participant. We assume that this is, among others, a reason for the low response. However, in interviews with residents and their spouses, these taboos and prejudices were far less present. The only major sign of taboos was that when physical sexuality was discussed, metaphorical language was used by some of the respondents. Bias is present, as it is of course true that residents and spouses who enrolled themselves in this research are comfortable in discussing their experiences and need for intimacy and sexuality. However, the comfort and sometimes-even relief in sharing these experiences that we encountered in the interviews make us assume that conversations on this topic in practice are more hoped for than presently engaged in. On top of that, the lack of communication with care staff was described as a barrier for residents and their spouses.

Finally, a major result of this study is the conclusion that love and intimacy, and to some extent sexuality, still mattered to residents with dementia and their spouses. Despite all limitations, barriers and emotional dilemmas, love, being together and protection of the spouse with dementia were of utmost importance. Emotional and physical intimacy, expressed in various behaviors, was found to be an important expression of this need for love and being together.

Part C. Attitudes of care staff: a closer look in a wider perspective

Results from the final quantitative study among employees of care organizations presented in Part C (Chapter five) indicated that their attitudes towards resident sexuality were significantly and positively influenced by two organizational factors: person-centered care and a supportive culture within the organization. Employees of care organizations who feel that they provide more person-centered care and feel that they work in an organization that supports them, have more liberal attitudes towards the sexuality of residents. From a person-centered care perspective, this seems logical, because providing more person-centered care implies regarding residents in a holistic way (Edvardsson et al., 2008; McCormack et al., 2010), including taking into account their sexual needs. These needs, however, were not explicitly mentioned in the literature on person-centered care. The significant influence of a supportive culture in the organization on care staff attitudes towards resident sexuality confirms the results and assumptions made by Roach (2004) that support is important for care staff to handle sexual behavior of residents. Her qualitative research described the presence of a "Guarding Discomfort Paradigm" in nursing home care. This means that care staff stands guard, in a reactive or proactive way, to avoid or decrease feelings of discomfort with regard to resident sexuality. Furthermore, the "guarding the guards" principle was included in this paradigm, which assumes that support in dealing with resident sexuality in a positive way is also very important for the job satisfaction of the employee (Roach, 2004).

In addition to the two organizational factors we found to be a significant influence on care staff attitudes, we also discovered that the believed presence of policy was a significant influence. This effect was, however, contrary to what we, and researchers in previous publications, expected. Staff members who reported that no policy or guideline was present showed more positive attitudes towards resident sexuality. Although we did not investigate the cause of this effect, we assume that employees who have very positive attitudes towards resident sexuality know that their organization has no policy or guideline with regard to resident sexuality, whereas employees with less positive attitudes assume their organization does. This implies that organizations should enhance awareness of their policy and guidelines, when these are present.

In previous research on care staff attitudes towards resident sexuality, several individual factors were identified as having an impact on these attitudes (see section "the research field: literature"). However, factors such as age, level of religiousness and level of education are not easy to change. We aimed at improving the possibilities of residents with dementia and their spouses to experience intimacy and sexuality in the way they want. A further implementation of a person-centered care paradigm, and propagating a supportive culture for the employees that includes intimacy and sexuality in the holistic view of the resident that characterizes this paradigm, can hopefully bring this aim closer.

Strengths and limitations

This doctoral thesis is characterized by several strengths and limitations. First, a major strength of this thesis was the equal collaboration between practice and research that was the base of the design and was maintained throughout the process. As the preface discussed, this thesis originated from an issue encountered in daily dementia care practice and throughout the process, the research questions, design, procedure and interpretation of the results were composed in collaboration with caregivers, HCP's and care managers. This resulted in a permanent connection with care practice. In frequent meetings between researchers and practitioners, results were discussed, which obliged us (the researchers) to explain all procedures and analyses and have the practice situation on top of our mind. Furthermore, valorization was not just an issue now that this study has come to an end, but all the way through, as through the collaboration results had to constantly be put in a practice perspective. Moreover, the collaboration will be continued through a project to transfer the results from the study into usable knowledge for practice.

A second strength of this study is the broad perspective on the theme of intimacy and sexuality taken in this thesis. The current research field of intimacy and sexuality can be divided into three sections: reported intimate and sexual behavior, knowledge and attitudes of care staff, and ethical and theoretical considerations. Research that has adopted one of these three focuses has often been insular in its perspective, ignoring the other two. This has caused the development of three separate "research fields" on the same subject. This is the first study to our knowledge to study intimacy and sexuality in RCF residents with dementia both from the perspective of clients and their spouses and that of care staff of nursing homes. This enabled a more nuanced and in-depth look at a complex issue where prejudice and taboo were an issue for all parties. Through the study among residents with dementia and their spouses presented in part B, we found that love, being together and intimacy on different levels were very important for them, despite all prejudices and taboo, on top of the found barriers.

Third, the client perspective was included. This resulted in rich, in-depth understanding of the way residents with dementia and their spouses make sense of their experiences regarding love, intimacy and sexuality. Furthermore, the inclusion of the spouses of the residents deepened the understanding, as the spouses could help with putting information into perspective and provide additional information. This perspective was, to our knowledge, unprecedented with this specific participant group. The client perspective had previously been neglected in research, which is surprising considering that this is a private matter that it would be difficult to obtain detailed, valid information about from any other perspective. This is, however, true for several themes which are ethically sensitive (Preshaw, Brazil, McLaughlin, & Frolic, 2016). In addition to the methodological considerations described before, ethical issues in methodology had to be addressed thoroughly to make this study possible.

This was performed in collaboration between research and practice, and subsequently described and published. Although it was a complex process, the valuable results and small start in understanding of the experiences of residents with dementia and their partners made it all worth it.

Fourth, in this study, we deliberately focused on normal or healthy intimacy and sexuality of all nursing home residents with dementia who reside in a psychogeriatric unit. This inclusive approach concluded in a general overview on this theme from different perspectives. The background of this resident population in nursing homes is diverse. The occurrence of dementia does not (in general) discriminate between people. Moreover, needs for intimacy and sexuality are not exclusive to a specific group of people. This is why we think this inclusive approach, in contrast to selecting a subgroup based on sexual orientation for example, was appropriate as a start in this research field. Furthermore, we deliberately chose to focus on normal or healthy experience and needs for intimacy and sexuality. Although problematic behavior, including sexually problematic behavior, is more salient in practice, we felt that this research was a great opportunity to provide confirmation of and publicity for the fact that needs for love, intimacy and sexuality do not expire when people age, or get dementia.

On the other hand, close collaboration between research and care practice also resulted in a main limitation that can be considered as a downside of the design of the project. A balance between research and practice was sometimes hard to find. A limitation from the practice point of view is the slow process and long time between composition of the research question and presentation of the results of the research. Furthermore, results from this study, like the results of most scientific research, are not directly transferable to daily care practice. Although we tried along the way to involve practitioners as much as possible (see strengths) and a “translation” project will start right after the completion of this study, for practical purposes, waiting four or five years before practical usable results are present seems very long. A limitation from the research point of view is the practice based background and results. Although scientific literature and methodology were the foundation of the studies’ design, they were also very much a product of practice and were designed with the objective of guiding future practice. This resulted in not comprehensively including theoretical backgrounds from research fields such as care ethics, management theory or sexology, for example. This also applies to the results of this study. Elaborating on our research question, which was fairly practical in nature, the results of this study do not test an existing model or translate into a new scientific theory or model.

A second limitation lies in the integration of the three different perspectives of this study. The design and consecution of the three different studies presented in this thesis were established ahead of the execution. The sequential timing—literature study first, qualitative study second and finally the quantitative study—seemed straightforward and convenient during the design phase of the study. Although we

were able to integrate the results of the three different studies, providing an overview of the theme, a multiphase or emergent study design, in which the next study would build on the previous one and the approach (quantitative, qualitative) would be chosen accordingly, would be ideal (Cresswell & Plano Clark, 2007). In this way, an even more matching and integrated image of the topic at hand could have been provided.

Although a major strength of the study, the inclusion of nursing home residents with dementia also imposed several limitations on methodology and analysis. First, the process of recruitment, selection and consent unavoidably resulted in a biased sample, because the sample had to consist of (1) residents who were cognitively able to participate in an interview, (2) residents and spouses who felt comfortable talking with a researcher about their experiences and needs for intimacy and sexuality, and (3) residents whose authorized representatives assessed their loved ones would want to and were able to participate in this study. Although we aimed at including residents with dementia in the preparation process as much as possible, in the Netherlands, nursing home residents with dementia, who reside in a psychogeriatric unit, are considered incapable of providing informed consent to participation in scientific research. Second, the analysis of the gathered data involved various limitations. The same researcher held all interviews. On the one hand, this proved a strength because of the experience of the researcher in having conversations with residents with dementia and their spouses, on the other hand it proved a limitation because of the bias it could have caused. The researcher was working in a nursing home, as a psychologist, which preoccupies the image, and instantly puts the information shared by the participants in a "nursing home frame." Furthermore, during the analysis process different limitations arose, as the interviews were only audio-recorded. Although field notes were made during the interviews, non-verbal signs from the participant proved to be very important in understanding the verbal stories. Field notes alone proved not to be sufficient for the non-interviewing researchers to interpret the interviews correctly and understand everything. More explanation from the interviewer was necessary. However, we deliberately chose to not capture the interviews on video, or work with a co-interviewer. Both would have been disruptive to the contact between interviewer and participant, as participants can become insecure or even frightened. Third, study quality in qualitative research is enhanced by a variety of criteria (Devers, 1999). We tried to meet most of the criteria—for example, achieving external validity by providing extensive descriptions of methodology, and reflexivity by co-coding and being aware of bias brought in by the interviewer (Devers, 1999). However, other criteria or common used techniques in qualitative research, such as performing "member checks," were not possible due to the memory impairment of different participants. However, we could have performed this for the spouse interviews, which we did not do. Finally, we chose to not objectively measure the cognitive impairments of the participating residents with

dementia. Although specific cognitive and physical abilities had to be sufficient to be able to participate in an interview, the manifestations of impairments and their severity can vary greatly over short periods of time. Moreover, we wanted to limit the burden of participation in the research as much as possible. Assessment of cognition can be a great burden for people with cognitive impairment, as it confronts them with their disabilities. Furthermore, we did not think the information gathered from these tests would add up in comparison to the burden caused.

The final limitation concerns the measures to assess knowledge with regard to resident sexuality and the culture of the organization used in the quantitative study. First, in the knowledge part of the ASKAS questionnaire (Mahieu, Dierckx de Casterle, Van Elssen, & Gastmans, 2013; White, 1982), higher scores are granted to respondents who admit to not knowing an answer, in comparison to participants who give a wrong answer. Although the questionnaire was well described and used before, we found this counterintuitive. We did, however, use the questionnaire in the described way, as it was also validated in this way. Second, the results of the FOCUS questionnaire, used to assess the culture of the organization, were divided into eight different scales, and consequently, eight variables. Reliability of two of these variables was found insufficient, so these variables unfortunately could not be used in further analyses.

Implications for future research

Next to the obviously necessary replication of our findings, several implications for future research can be derived based on the findings of our study.

First, a general implication lies in the way research questions are defined. As practical implications of research are considered increasingly important as, for example, valorization possibilities need to be addressed in research projects, more researchers should pick up important research topics directly in (care) practice. Especially in a social science, such as the science field of care research, strong cooperation between researchers and employees of care organizations seems beneficial for both, as researchers will understand the stubborn practical care situation better, and practitioners will understand and hopefully value the complex and slow research process more. Interesting and relevant research topics are plentiful in practice; they just have to be discovered and defined by researchers. Furthermore, scientifically based (evidence based) information is vital to improving (nursing home) care practice today and helps to find solutions for the problems of tomorrow.

Second, another general implication for research in the field of dementia care is the inclusion of the person-centered perspective of people with dementia, which is recognized to be increasingly important in clinical care practice and in research (Edvardsson et al., 2008; McCormack et al., 2010). However, in research, this perspective is rarely represented, especially when it concerns people with moderate to severe degrees of dementia, who live in protective living environments such as

psychogeriatric units of nursing homes. This is imaginable, as these people make difficult participants in scientific research for several reasons that are described in the section on methodological considerations. However, the included client perspective in this study is of great value to the final results as an important perspective to complete the overview of such private topics. We hope this study will be considered as a confirmation that it is possible to include these people in research. Moreover, we hope it will be an encouragement to include the client perspective in more research, especially when concerning private or sensitive topics that are encountered in daily dementia care, as this perspective adds to ethical considerations in research and practice.

Third, more specific research is needed in the area of intimacy and sexuality in people with dementia, but from different perspectives and from a wide view in terms of content. Based on the literature review (Part A), it was concluded that the research on intimacy and sexuality in people in old age, and people with dementia specifically, was performed in a fragmentary way. Different (individual) researchers and practitioners performed small pieces of research on the topic. Although they are valuable in their own right, in the subject of intimacy and sexuality in nursing home residents with dementia a full research line or overview is lacking. This study can be considered as a small first step towards an integrated view of the topic, although a lot of work still needs to be done. A direct follow-up of this study could be performed to increase the understanding of the attitudes of RCF employees, with regard to resident intimacy and sexuality, for example. Through the quantitative study presented in Part C, we learned that organizational factors influence these attitudes, but a qualitative follow-up study could yield understanding of how employees experience these organizational factors (person-centered care and the culture of the organization) to be of influence.

We also encountered a distinction between concepts. The quality of relationships, love, intimacy and sexuality were assessed separately in previous research. Especially in research with regard to attitudes of care staff with regard to resident sexuality, relationships, love and intimacy were totally ignored. A major conclusion from this research is that these concepts cannot be seen separately when considering nursing home residents with dementia and their spouses. We do suggest including all these coherent topics in future research and, for example, include these in topic lists for qualitative research and questionnaires for quantitative research.

Fourth, as described in the preface of this thesis, we deliberately chose to focus this research on “normal” or “healthy” intimacy and sexuality of residents with dementia. In daily care practice intimate or sexual “problem” behavior tend to be recognized and discussed regularly, while normal and healthy needs for intimacy or sexuality are rarely discussed, or recognized in this way. van Hooren (2011) stressed earlier that a clear distinction between this normal behavior and problematic behavior would help to focus in research and practice(Hooren, 2011)(Hooren, 2011)(Hooren,

2011)(Hooren, 2011). The results of this study provide insight into the experiences of normal or healthy aspects of love, intimacy and sexuality from the perspective of residents with dementia and their spouses. However, caregivers or other members of the care staff (e.g., MD's, psychologists, and team mangers) most frequently define what constitutes normative or problematic behavior. To clearly distinguish between normal and problematic behavior, the perspective of care staff on this distinction should be compared with the client perspective. This was, however, not the scope of this research. The definition of this distinction remains a goal and need for investigation in further research, in which we hope the client perspective will not be ignored.

Fifth, gender was found to be a major issue in attitudes with regard to resident sexuality, although it was not reported as a main result of a study. Despite the small sample of their study, the study of Ward et al. (2005) gave a peek at this issue. They found that female caregivers reported more sexual behavior in male residents and perceived this behavior as more problematic compared to two male care staff members who reported the opposite (more sexual behavior in females and perceived this as more problematic)(Ward et al., 2005). Unfortunately, the gender distribution in the sample of our final quantitative study was not suitable to perform analysis to explore this further. This task remains for future research.

Finally, in this study we did not define participants, either residents or care staff, by their sexual orientation. During the course of this study, other researchers, policy makers and practitioners questioned whether the position of non-heterosexual residents was explicitly studied. In the Netherlands, a movement to endorse publicity for nursing home residents with different sexual orientations started and spread successfully over the country. Through this movement, different initiatives for day treatment and awareness programs for employees of nursing homes were developed. We deliberately did not distinguish based on sexual orientation in this study, as we aimed for this study to be as inclusive as possible. However, experiences with regard to love, intimacy and sexuality in nursing home residents with a non-heterosexual orientation could be different from those of a heterosexual resident or their partner and we think that would therefore be interesting to investigate in future research.

Implications for clinical practice

Different implications for clinical practice can be drawn from this study. As the research question was drawn directly from practice, this seems to be a good starting point to define implications for clinical practice:

> In what way can nursing home residents with dementia, and possibly their partners, be best supported in their wishes and needs with regard to intimacy and sexuality?

These implications can be divided into three levels. First the client perspective is highlighted. Implications from this perspective focus on improvement of the perspective and feelings of residents with dementia and their spouses on a daily basis. These implications could be included in care today. Second, implications on the organizational level are highlighted: these are defined on the level of individual care organizations. Finally, implications on a general level of dementia care are highlighted. These exceed the possibilities of individual care organizations and will take the most time to include.

The level of client perspective. On the level of the client's perspective, we propose three implications for clinical practice. First, the inclusion of the client perspective in care on a daily basis, with regard to their friendships, relationships and experiences of love, intimacy and sexuality should be enhanced. A large diversity in experiences and needs was found in this study. This implies that knowledge of individual preferences and needs is necessary to provide individual facilitation and the care residents need. These individual preferences and needs should be assessed and included in care on a daily basis. This could be achieved through inclusion of the topic in admission forms, care plans and evaluations. Individual clients' preferences and needs should be taken into consideration throughout the everyday course of the client's residence. Furthermore, spouses or partners of residents should be involved in this assessment.

Second and consequently, communication of experiences and needs with regard to love, intimacy and sexuality should be enhanced in daily care. Residents and their spouses stated that they miss communication on this theme. An employee of the nursing home organization should take the initiative in this communication, as we have found that in residents and their spouses this subject is taboo at present. To enhance a feeling with residents and spouses that love, intimacy and sexuality are themes that can be discussed, an open or liberal attitude of direct caregivers, indirect caregivers such as medical doctors (MD), psychologists and care managers is essential.

Finally, although efforts of care staff to help residents with dementia and their partners with their needs for intimacy and sexuality were recognized by residents and their spouses, it seemed to be very difficult to do this in the right way. Creating a situation within the nursing home that helps residents and their spouses to feel comfortable and safe "just like home" is not straightforward in a nursing home situation. Unfortunately, we do not expect an easy solution will be found on this matter, although we hope small steps of improvement on the individual client level will improve the possibilities.

The organizational level. First, improving knowledge of resident sexuality was repeatedly found to positively influence the attitudes of care staff with regard to resident sexuality. Moreover, throughout the literature, the absence of training programs to increase this knowledge was pointed out. Consequently, this seems a

straightforward implication for clinical practice. However, as part of these training programs, not only knowledge should be enhanced. A training program can also be considered as an opportunity to improve attitudes and reduce stigma directly.

Second, not only in this study but also in previous research, the importance of policy and guidelines with regard to resident sexuality for RCF practice was stressed. Although expected, conversely, we found that care staff that reported that a policy or guideline was present in their organization reported less open attitudes towards resident sexuality. However, it was not assessed whether this policy or guideline was actually present or not. We therefore assume that employees who hold liberal and open attitudes towards resident sexuality searched for a policy or guideline and did not find one. Policies and guidelines based on person-centered care, supported by all levels in the organization and implemented in daily care can help employees to deal with expression and needs for love, intimacy and sexuality of residents with dementia.

Finally, implementing a supportive culture and increasing person-centered care on all levels of the organization was proved to be important for care staff attitudes on resident sexuality. However, as previously mentioned, a more supportive organizational culture will also enhance improvement on other sensitive issues (Preshaw et al., 2016). Changing a culture in an organization is not straightforward and this certainly applies to care organizations. Care organizations consist of largely independent and strong collaborative teams, who all have their own norms and character.

The level of dementia care

First, although the initial subject of the study was: "Intimacy and sexuality in nursing home residents with dementia," through the course of the study intimacy and sexuality proved to be embedded in the concepts of "relationship" and "love" and we did not solely look at residents with dementia, but included their spouses intensively. In dementia care practice; intimacy and sexuality are rather isolated themes. For example, in the case of a resident who expresses intimate or sexual behavior, the initial thought of caregivers is that of problem behavior, and not that of an expression of a normal or healthy need for intimacy, embedded in a love or relationship history. However, this image should change in a wider view on relationships, the expression and experience of love of residents and their spouses, and the place that intimate and sexual expression takes in this important aspect of peoples' lives. It sounds obvious that residents with dementia have lifelong experiences with regard to love, intimacy and sexuality behind them. However, in nursing home practice, this love history, including the history of peoples' intimate and sexual lives, is mostly neglected.

Second, in reviewing the results of the complete thesis, not only information on intimacy and sexuality in residents with dementia arises, but also an image of a sensitive topic within dementia care in general is uncovered. As stated in section A and C, despite the paradigm shift that is taking place in this care field into a more

person-centered care paradigm, protection is still an important factor in dementia care. This seemed even more evident with regard to residents' expression of intimacy and sexuality. Although the culture of the pure medically oriented view is slowly disappearing, the general perspective on residents with dementia is one of people who are vulnerable that need to be taken care of and protected against harm and offence. This is, of course, at least partly right. Moreover, with regard to the expression of sexuality, the personal discomfort of the care employee increases as a result of these protective attitudes, which was described by Roach (2004) as the "Guarding Discomfort Paradigm." It is debatable whether this is right or necessary. To achieve the next step in perceiving residents with dementia holistically and as people rather than patients (Edvardsson et al., 2008), hidden ethical issues should be uncovered and addressed on a scale which is larger than a single care organization. The general view on residents with dementia should gain "person-centeredness."

Conclusion

This thesis gave, for the first time, insights of a broad and holistic perspective on intimacy and sexuality in nursing home residents with dementia and their spouses, through a close collaboration between research and practice. Although the client perspective was largely neglected in previous research, this perspective did uncover a new and person-centered view on the topic. This will hopefully increase understanding and consequently increase possibilities for residents and their spouses to experience intimacy and sexuality in the way they want. Despite barriers on biological, psychological and social levels, residents and their spouses indicated that love, being together, intimacy and to some extent sexuality are still of great importance to them. Attitudes of care staff were assumed and reported to, among others, influence the possibilities of residents and their spouses to experience intimacy and sexuality in the way they want. A culture in the organization in which care staff feels supported and provide person-centered care was found to improve the attitudes of care staff. We hope this thesis will inspire and encourage researchers to study intimacy and sexuality in nursing home residents with dementia also in such a broad and person-centered perspective and consequently build upon a cohesive research field on this topic. In our opinion, the collaboration between research and practice proved to provide great contributions for such sensitive and person-centered studies.

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Nederlandstalige Samenvatting

Vragen rondom intimiteit en seksualiteit van mensen met dementie komen regelmatig naar voren in de praktijk van de verpleeghuiszorg. Deze vragen richten worden vaak gesteld in het kader van probleem- of onbegrepen gedrag, wat mij als ouderenpsycholoog verbaasde. Hebben mensen met dementie geen gezonde behoefte meer aan intimiteit en seksualiteit? Wordt dit gedrag als zodanig moeilijk ervaren dat het altijd als een probleem of ontremming wordt gezien? Een korte studie leerde dat ook in het wetenschappelijke veld tot nog toe weinig aandacht is geweest voor dit thema. Om voor zowel praktijk, als wetenschap een zinvolle bijdrage te leveren is dit onderzoek zo opgezet dat praktijk en wetenschap gelijkwaardig betrokken zijn.

Achtergrond

Ondanks dat er vooroordelen spelen rondom intimiteit en seksualiteit bij ouderen, blijkt dat mensen tot op hoge leeftijd seksueel actief zijn. Belangrijker nog, het hele spectrum van intimiteit en seksualiteit zijn en blijven belangrijke aspecten van het leven en de kwaliteit van leven voor mensen, ongeacht hun leeftijd. Wel veroorzaken biologische (fysieke), psychologische en sociale factoren dat, vooral aan de kant van het spectrum van seksualiteit, frequentie en intensiteit afnemen.

Voor mensen met dementie spelen, naast de bio-psycho-sociale factoren, ook beperkingen die bij dementie horen, zoals geheugenverlies of desoriëntatie, die de mogelijkheid om intimiteit en seksualiteit te beleven bemoeilijken. Wanneer de dementie verergerd naar een mate waarin thuis wonen geen mogelijkheid meer is, verhuizen mensen vaak naar een psychogeriatrische afdeling van een verpleeghuis. In deze afdelingen of woongroepen, wordt met een gevarieerd aantal cliënten samen geleefd, en is er 24-uur per dag verzorging aanwezig.

Mensen met dementie (v.a. nu cliënten) zijn afhankelijk van deze zorg en begeleiding op alle terreinen van het leven. Deze afhankelijkheid zorgt voor een sterke inperking van de privacy en mogelijkheid zelf beslissingen te nemen. Het is dan ook voorstelbaar dat het beleven van intimiteit en seksualiteit naar wens en behoefte van de cliënten en (mogelijk) diens partner, ernstig belemmerd is.

De laatste jaren wordt persoonsgerichte zorg als concept van steeds groter belang in de psychogeriatrische verpleeghuiszorg. Waar vroeger voornamelijk zorg werd geboden op basis van een medisch model, wordt nu het vergroten van de kwaliteit van leven van cliënten als het doel van de zorg en begeleiding gezien. Zoals eerder gesteld zijn intimiteit en seksualiteit zijn hiervan ook belangrijke aspecten, maar deze worden in de praktijk nog onderbelicht. Daarnaast worden in de praktijk intiem en seksueel gedrag van cliënten met dementie vaak als probleemgedrag of ontremming ervaren.

Aansluitend bij de persoonsgerichte benadering, wordt in dit onderzoek het cliëntperspectief centraal gesteld. De centrale onderzoeksvraag voor deze thesis was:

> Hoe kan er zo goed mogelijk ingespeeld worden op de wensen en behoeften van mensen met dementie in het verpleeghuis, als het gaat over intimiteit en seksualiteit?

Het onderzoek heeft een exploratief ontwerp waarin zowel kwalitatieve, als kwantitatieve onderzoeksmethoden zijn gebruikt. De thesis en deze samenvatting zijn verdeeld in drie onderdelen. In deel A wordt de systematische literatuurstudie uitgewerkt. Hierin wordt een overzicht gegeven van de recente literatuur aangaande intimiteit en seksualiteit van cliënten met dementie. Deel B start met de samenvatting van de methode van het kwalitatieve deel van het onderzoek naar het cliëntperspectief van cliënten en hun partners met dementie, ten aanzien van liefde, intimiteit en seksualiteit. Vervolgens worden de resultaten van de hoofdstukken drie en vier van de thesis in samenvatting gegeven, waarbij in hoofdstuk drie de resultaten van de interviews met koppels en individuele cliënten worden behandeld; en in hoofdstuk vier de resultaten van de interviews met partners van cliënten. In deel C wordt een samenvatting gegeven van de kwantitatieve studie naar effecten van organisatorische factoren op de attitudes van medewerkers van verpleeghuizen, ten aanzien van seksualiteit van cliënten met dementie. Tot slot worden de thesis en deze samenvatting afgesloten met een algemene discussie.

Deel A

Het opstellen van een gestructureerd overzicht van empirische, wetenschappelijke kennis aangaande gezonde intimiteit en seksualiteit bij mensen met dementie die in een verpleeghuis wonen, was het doel van deze systematische literatuur studie. Uit de 215 gevonden artikelen, bleven na exclusie 12 geschikte artikelen over. Zeven studies vonden plaats in Amerika, drie in Groot-Brittannië, een in Israël en een in Taiwan. De studies waren divers in focus, onderzoeksmethodologie en kwaliteit. De studies zijn met behulp van de Mixed Methods Appraisal Tool (MMAT) getoetst op kwaliteit.

Twee hoofdthema's kwamen naar voren als focus van de geïncludeerde studies; geobserveerd intiem en seksueel gedrag van mensen met dementie en kennis en attitude van zorgverleners. Als het gaat over geobserveerd gedrag werden zeer diverse gedragingen gerapporteerd, die het volledige spectrum van vriendschap, liefde, intimiteit en seksualiteit behelsden. Deze gedragingen werden geobserveerd door onderzoekers, of door zorgverleners.

Als het gaat over kennis en attitude van zorgmedewerkers werden verschillende factoren gerapporteerd die op deze kennis en attitude effect hadden. Over het algemeen werden er een neutrale of positieve attitude gerapporteerd door zorgverleners. Het bleek echter dat leeftijd, opleidingsniveau en religiositeit invloed hadden op kennis en attitude ten aanzien van seksualiteit van cliënten.
Verder bleken wilsonbekwaamheid en de mogelijkheid van de mensen met dementie om wel of niet in te stemmen met intimitiet en seksualiteit een belangrijk thema. Dementie bij cliënten bleek voor ethische dilemma's te zorgen, rondom het thema seksualiteit. Hierbij werden juridische zorgen, veiligheidszorgen, zorgen rondom het wel of niet betrekken van familie en zorgen rondom verschillen in cognitieve capaciteiten tussen cliënten genoemd.

Ook gender kwam naar voren als thema. Vooral in de studies naar kennis en attitude van seksualiteit van zorgverleners kwam naar voren dat seksueel gedrag het meeste werd ervaren bij mannelijke cliënten. Dit werd niet alleen meer frequent gerapporteerd, maar werd ook vaker als probleemgedrag ervaren dan seksueel gedrag van vrouwelijke cliënten. In een van de studies waren ook een aantal mannelijke zorgverleners geïncludeerd, waarbij een tegengesteld effect leek op te treden.
Ten slotte werd er in de artikelen gesproken over de zorgcultuur en werden trainingsprogramma's en protocollen rondom intimiteit en seksualiteit bij deze doelgroep voorgesteld om kennis en attitude te verbeteren. De zorgcultuur werd in de literatuur als beschermend gekwalificeerd, zeker als het gaat over cliënten met dementie.

Deze studie werd gekenmerkt door een aantal beperkingen. Er was bijvoorbeeld geen toegang tot de database CINAHL. Ook bleek de kwaliteit van de geïncludeerde studies in het algemeen matig te zijn.

De belangrijkste conclusie die uit dit literatuur overzicht getrokken kan worden is dat het cliënt perspectief nog niet belicht is in de wetenschappelijke literatuur. Dit is vreemd gezien het persoonlijke onderwerp en de grote individuele diversiteit als het gaat over intimiteit en seksualiteit. Daarnaast kwam uit de literatuur een beeld van een beschermende zorgcultuur naar voren, waarbij het feit dat iemand dementie heeft een extra lading geeft aan het thema. In de literatuur wordt dan ook gesproken over het "halo effect" van dementie, waarbij gesteld wordt dat een dementie diagnose gelijk staat aan het wegvallen van alle beslissingsbevoegdheid en wilsbekwaamheid.

Deel B

Zoals uit de literatuur review naar voren kwam, was het cliënt perspectief aangaande intimiteit en seksualiteit bij mensen met dementie in het verpleeghuis, nog niet eerder belicht in de wetenschappelijke literatuur. De start van deel B bestaat uit een uiteenzetting van de methode van de volledige studie naar het cliëntperspectief van mensen met dementie en hun partners ten aanzien van intimiteit en seksualiteit,

te vinden in hoofdstuk 2 van de thesis. Er is kwalitatief onderzoek gedaan naar dit perspectief, met behulp van interviews. Gedegen overwegingen en keuzes ten aanzien van ontwerp en methode van onderzoek zijn zeker gangbaar in de wetenschappelijke onderzoekspraktijk. Echter, gezien de groep cliënten waar het hier over gaat; mensen met dementie die in een verpleeghuis wonen, en hun partners en het onderwerp, was het noodzakelijk ontwerp van het onderzoek nog beter te doordenken en voor te bereiden. De beschreven uiteenzetting behelst ook de overwegingen vooraf en reflecties achteraf op deze methode, met als doel om andere onderzoekers te informeren, maar ook zeker aan te moedigen het cliëntperspectief van mensen met dementie in onderzoek te includeren.

Er is in deze studie gekozen voor een kwalitatief studie ontwerp, wat specifiek vormgegeven werd volgens de Interpretative Phenomenological Analysis (IPA) methode. Deze methode gaf ons de ruimte om diep in te gaan op de ervaringen van mensen en hoe mensen deze ervaringen een plaats geven in hun persoonlijke leefwereld. Het praktische deel van het ontwerp werd in gelijkwaardige samenwerking tussen onderzoekers en praktijk vormgegeven. Vooraf hebben twee groepsdiscussies plaatsgevonden om details in het ontwerp en de ethische verantwoording van de studie goed te doordenken. Aan deze discussies namen zowel onderzoekers, als professionals uit de praktijk deel. Hierbij moet gedacht worden aan een zorgmanager, psychologe en zorgmedewerkers.

Voor de ethische toetsing van deze studie is het onderzoeksvoorstel eerst voorgelegd aan de Medisch Ethische Toetsingscommissie (METC) van Brabant, om na te gaan of deze studie onder de Wet Medisch-Wetenschappelijk onderzoek met mensen (WMO) zou vallen. Nadat dit niet zo bleek te zijn is de studie getoetst door de Psychologisch Ethische Toetsingscommissie (PETC) van Tilburg University, die de studie goedkeurde.

De procedure van het onderzoek behelsden werving van proefpersonen, inclusie en exclusie en de procedure rondom toestemming. Deze procedure is te vinden in Figuur 1. De werving van de proefpersonen startte met het verkrijgen van informatie van de deelnemende organisaties. Daarna werden de wettelijk vertegenwoordigers benaderd. Deze procedure via de wettelijk vertegenwoordiger is gekozen omdat de cliënten binnen de psychogeriatrische verpleeghuiszorg als wilsonbekwaam worden gezien. Nadat een wettelijk vertegenwoordiger, zichzelf in het geval van een partner, wel of niet samen met een cliënt, heeft aangemeld voor deelname vond er een introductie gesprek plaats. Bij dit gesprek waren de wettelijk vertegenwoordiger, de eerste verantwoordelijk verzorgende en de onderzoeker aanwezig. Hier werd de mogelijkheid tot deelname besproken en wanneer dit mogelijk was, ook de procedure voor toestemming en de randvoorwaarden voor het interview. De procedure voor toestemming kende drie varianten, die ook in Figuur 1 staan uitgewerkt. Waarna het interview plaatsvond.

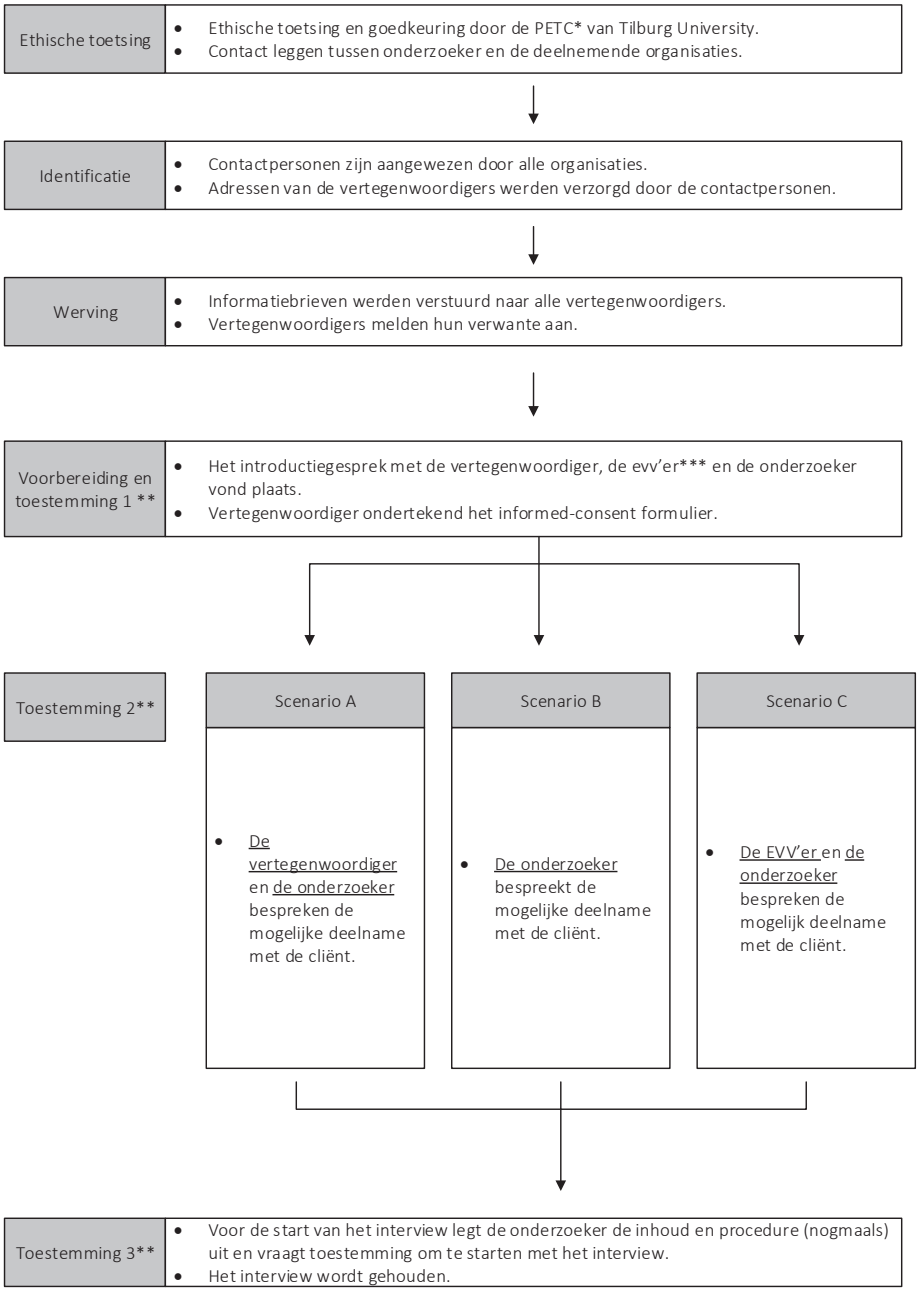
Vooraf aan de uitvoering van het onderzoek is ook gedetailleerd gekeken naar de inhoud en de vormgeving van het interview. Uit de literatuur kwam naar voren dat een flexibele en semi-gestructureerde methode belangrijk was in het interviewen van mensen met dementie. Wanneer het gaat over het interviewen over een gevoelig onderwerp, zoals intimiteit en seksualiteit, werd geadviseerd om de onderwerpen in gevoeligheid te laten oplopen; te beginnen bij vriendschap en te eindigen met seksualiteit. Uiteindelijk is het schema van onderwerpen tijdens de dataverzameling gewijzigd op basis van de ervaring van de interviewer, bijvoorbeeld het thema erotiek is verweven in seksualiteit, omdat proefpersonen deze constructen niet als verschillend zagen. Daarnaast bleek de ruimte waar het interview plaatsvond belangrijk en ook de ervaring van de interviewer met gesprekken voeren over gevoelige onderwerpen met cliënten met dementie en hun partners en. Uiteindelijk bleek het bijhouden van veldnotities van opvallende zaken tijdens het interview, die later in de analyse zijn meegenomen, ook van grote waarde. De interviews zijn opgenomen met een audiorecorder. Er is bewust gekozen om niet met een videocamera te werken, omdat dit voor cliënten en mogelijk hun partners, erg beangstigend kan zijn.

De data is geanalyseerd aan de hand van de IPA methode. Hierdoor kon de rijke data, bestaande uit transcripten aangevuld met notities en observaties, op case niveau geanalyseerd worden. Dit was ook van belang aangezien er veel figuurlijke taal werd gebruikt door de proefpersonen, zeker om de meer gevoelige onderwerpen duidelijk te maken.

Het bewaken van de kwaliteit tijdens het uitvoeren en analyseren van kwalitatief onderzoek en data is uitgebreid beschreven in de literatuur. Tijdens het ontwerp en uitvoering van het onderzoek moesten er echter keuzes worden gemaakt om de balans in het hanteren van de kwaliteitsstandaarden en de praktische uitvoerbaarheid te bewaren. Een voorbeeld hiervan is het niet uitvoeren van zogenaamde ‘member checks’, maar wel extra aandacht besteden aan reflectie en externe validiteit.

De studie werd uitgevoerd binnen drie zorgorganisaties in Brabant. Dataverzameling vond plaats binnen de psychogeriatrische afdelingen van deze organisaties, met uitzondering van de afdelingen waar ik zelf als psycholoog aan verbonden was. In totaal zijn er 17 interviews gehouden. Vier interviews werden met koppels gehouden en vier met individuele cliënten, die weduwe of weduwnaar, of alleenstaand waren. Deze acht interviews werden als een dataset gezien en geanalyseerd. Op basis van deze analyses is het derde hoofdstuk van deze thesis geschreven. Er werden ook negen interviews gehouden met partners van cliënten met dementie. Ook deze interviews werden samengevoegd in een dataset en zodanig geanalyseerd en beschreven in het vierde hoofdstuk van deze thesis.

Ten slotte wordt in de uiteenzetting van en reflectie op de methode dieper ingegaan op de beperkingen van de huidige studie en aanbevelingen voor verder onderzoek. Ten eerste ten aanzien van de voorbereiding bleek de samenwerking van onderzoekers en professionals uit de praktijk van grote meerwaarde voor het verdere verloop van de studie. De gedetailleerde voorbereiding had meer voordelen, maar zou echter niet de flexibiliteit tijdens de uitvoering van de studie in de weg moeten staan. Bijvoorbeeld ten aanzien van het interview schema, hier was zeer goed over nagedacht en was besproken tijdens de groepsdiscussies, uiteindelijk bleek dat dit toch aangepast moest worden.
Ten tweede ten aanzien van de procedure, bleken het introductie gesprek en de intensieve betrokkenheid van de wettelijk vertegenwoordiger en eerste verantwoordelijke verzorgenden hierin van grote waarde. Dit heeft er bijvoorbeeld toe geleid dat, ondanks dat er geen objectivering van cognitieve functies van cliënten is gemaakt ter in- of exclusie, alle interviews rijke data opleverden, zonder dat cliënten onrustig werden of het interview andere negatieve gevolgen had. Ook was de voorbereiding van de interviews en de ervaring van de onderzoeker van belang.
Ten slotte ten aanzien van de data analyse en studie kwaliteit bleek dat de balans tussen het bewaken van kwaliteit en de uitvoerbaarheid goed in balans te moesten zijn.
Concluderend kan gesteld worden dat het includeren van het cliëntperspectief van psychogeriatrische cliënten en hun partners in onderzoek naar ervaringen aangaande intimiteit en seksualiteit uitgebreide, rijke inzichten heeft opgeleverd, die duidelijk opwegen tegen de moeite die het heeft gekost in de voorbereiding en uitvoering van het onderzoek. Voor uitgebreide aanbevelingen, zie de appendix van hoofdstuk twee van de thesis.



Figuur 1. Stroomschema procedure van werving, inclusie en exclusie en de procedure rondom toestemming.

*PETC= Psychologisch Ethische Toetsingscommissie; **Toestemming;

***EVV'er= Eerste Verantwoordelijke Verzorgende

Individuele cliënten en koppels. In hoofdstuk drie zijn de resultaten gerapporteerd van de acht interviews met individuele cliënten met dementie (vier) en koppels, waarbij een van beiden cliënt is met dementie (vier). De koppels waren tussen de 17 en 50 jaar getrouwd; twee mannelijke cliënten, en een vrouwelijke cliënt met hun partner en het laatste koppel woonde beide samen binnen een psychogeriatrische afdeling van het verpleeghuis. Van de individuele cliënten waren drie mensen (twee mannen en een vrouw), weduwe en weduwnaars. De laatste individuele mannelijke cliënt, was altijd alleenstaand geweest.

Verschillende overeenkomstige thema's kwamen naar aanleiding van de kwalitatieve analyse naar voren. Zo bleek dat de cliënten en hun partners overeenkomstig uitgebreid vertelden over hun levens- en liefdesgeschiedenis en geschiedenis als het gaat om intimiteit en seksualiteit. De koppels brachten vooral verhalen naar voren uit de tijd dat ze elkaar ontmoeten en hun volwassen leven. De weduwe en weduwnaars vertelden voornamelijk over de tijd dat zij hun partners verloren. De huidige ervaringen rondom intimiteit en seksualiteit waren in de geschiedenissen en in het continuüm van samenzijn, liefde, intimiteit en seksualiteit ingebed.

Deze huidige ervaringen werden ook sterk gekleurd door het ziekte- en opnameproces van de partner of cliënt met dementie. Dit proces heeft een zeer grote invloed op de levens van de koppels en de individuele cliënten en ook op de manier hoe de relaties ervaren werden. Een donker en verdrietig gevoel kwam met deze verhalen naar boven, ondanks dat sommige cliënten en/of partners hun situatie wat probeerden te bagatelliseren.

Het samen zijn en loyaliteit naar elkaar beken heel belangrijk voor de cliënten en hun partners. Vooral in de verhalen van de koppels viel een zeer sterk loyaliteits- en beschermingsgevoel op. Het voorbeeld van een partner die een appartement kocht zeer dicht bij het verpleeghuis, om maar zoveel mogelijk bij zijn vrouw te zijn, is hier een van. Daarnaast werd verschillende keren aangegeven dat een partner geen behoefte had aan een nieuwe partner, en dit ook niet kon goedvinden voor zichzelf. Het beschermen van de partner met dementie kwam veelvuldig en letterlijk naar voren.

Liefde was voor zowel koppels als individuele cliënten zeer belangrijk. Dit hing sterk samen met de loyaliteit en bescherming, maar werd ook als apart thema veelvuldig benoemd. "Liefde is Alles", is hiervan een mooi voorbeeld.

Er waren weinig cliënten en hun partners die momenteel fysieke intimiteit en seksualiteit beleefden. Verschillende oorzaken voor de afwezigheid van deze beleving werden gegeven, waarvan fysieke problemen en ouderdom de belangrijkste waren. Deze beleving samen werd wel gemist. Een koppel verwoordde dit verder door aan te geven dat dit voor hen de diepe connectie uit hun relatie had weggenomen. Een koppel was wel seksueel actief samen binnen het verpleeghuis. Ze hadden dit met de zorg gecommuniceerd, en er was bijvoorbeeld een 'niet storen' bordje wat zij

konden ophangen op de slaapkamerdeur, om meer privacy te hebben. De gezonde echtgenote gaf echter aan dat, ondanks al deze inspanningen, een echt gevoel van privacy ontbrak. Dit werd ook door andere cliënten en partners zo aangekaart. Het creëren van een gevoel van privacy blijkt meer complex te zijn dan een gesloten deur. Ten slotte werden, naast de afwezigheid van het gevoel van privacy, nog twee barrières benoemd als het gaat over het invullen van intimiteit en seksualiteit in de huidige situatie van de cliënten en hun partners. Ten eerste richtte dit zich op de communicatie met elkaar, in het geval van koppels, en met de zorgprofessionals. Daarnaast werden een aantal praktische barrières benoemd, zoals eenpersoons bedden en plaatsgebrek, in de slaapkamer.

Uit deze interviews werd duidelijk dat liefde, intimiteit en seksualiteit voor de cliënten met dementie en hun partners belangrijke, en sterk in elkaar gevlochten aspecten van hun huidige leven waren. Het samen zijn en loyaliteit naar elkaar waren daarin het meest belangrijk, terwijl het ervaren van privacy het meest moeilijk was om intimiteit samen te beleven.

Het onderzoek werd gekenmerkt door een aantal beperkingen zoals de geringe grootte van de steekproef en specifieke voorwaarden die gesteld werden aan de cliënten, om te kunnen deelnemen aan een interview. Deze studie geeft echter een rijk, exploratief beeld van het cliëntperspectief als het gaat over intimiteit en seksualiteit, waaruit ook een aantal aanknopingspunten voor het verbeteren van de zorgpraktijk kunnen worden gehaald.

Echtgenoten/partners. In hoofdstuk vier zijn de resultaten gerapporteerd van de negen interviews met partners van cliënten met dementie. Alle koppels bleken getrouwd te zijn, met een lengte variërend tussen de 28 en 60 jaar. Zeven mannelijke partners namen deel en twee vrouwelijke, waarbij een van de mannelijke partners zelf ook zorg ontving binnen een verzorgingshuis; de anderen waren thuiswonend.
Het eerste overeenkomstige thema dat door alle partners werd aangesneden was de impact die het proces van dementie op hun geliefden, henzelf en hun relatie had gehad in het verleden en in het heden. Schrijnende verhalen over de manier hoe men de eerste tekenen van dementie had beleefd, vaak achteraf had beredeneert dat dit proces al langer gaande was en zoveel en zo lang mogelijk zorg bieden thuis tot aan het moeilijke moment dat dit niet meer ging kenmerkte de inleidingen van de partners. Voor veel partners was de periode vlak voor en rondom de opname van hun geliefde de meest moeilijke.
Hieruit vloeide het tweede thema rondom de veranderde relatie voort. Ondanks dat alle partners deze verandering benoemde, was de inhoud van de ervaringen verschillend; waar een aantal partners het gevoel hadden dat ze hun gelijkwaardige partner waren verloren, en hier niets voor in de plaats kwam, ervaarden anderen dat hun relatie meer vriendschappelijk was geworden.

Bescherming en voor elkaar blijven zorgen vormde het derde thema, waarbij ook de loyaliteit naar de geliefde met dementie naar voren kwam. Zowel impliciet, als expliciet lieten de partners merken het erg belangrijk te vinden dat hun geliefde niets overkwam en sommigen gaven aan ook graag nog zelf taken van de zorg uit te voeren. De grote loyaliteit werd ook duidelijk in het letterlijk benoemen van de geloften die partners hadden uitgesproken tijdens het huwelijk. Toch kwamen hier ook dilemma's bij kijken, wanneer het bijvoorbeeld ging over het emotioneel afsluiten en afscheid kunnen nemen van een geliefde die er in werkelijkheid nog is.

De opname van de geliefde had een grote impact op de relatie, en kwam als vierde thema uitgebreid aan bod. Het accepteren van de situatie bleek voor partners zeer emotioneel en moeilijk. Partners omschreven een proces van het stukje bij beetje afscheid nemen van hun geliefde. Een geruststelling was soms dat de geliefde het zelf niet zo in de gaten had.

Liefde bleek, als vijfde thema, echter voor de partners nog steeds zeer belangrijk en in sommige relaties nog steeds zeer aanwezig. Een partner vertelt dat hij nog steeds zo verliefd kan zijn op zijn vrouw, als toen ze elkaar net ontmoetten. Toch bleek het verlies van de liefde en het gemis van het niet meer bij elkaar zijn even groot.

Het beleven van intimiteit en seksualiteit bracht in de meeste gevallen dilemma met zich mee. Ondanks dat de meeste partners aangaven niet meer seksueel actief te zijn met hun partner, bleek (fysieke) intimiteit nog erg belangrijk. Hierbij werden voorbeelden genoemd als het vasthouden van elkaars hand of een mannelijke partner die door het haar van zijn vrouw streelt. Er werden in dit licht echter ook dilemma's besproken, waarbij bijvoorbeeld de geliefde met dementie duidelijk naar voren bracht dat hij of zij behoefte had aan het samen slapen of verdere intimiteit. Aan de ene kant wilden de partners aan dit verzoek gehoor geven, maar hun eigen gevoel of het idee dat ze misbruik zouden maken van hun partner hield hen dan tegen.

Ten slotte werd de ervaring en mogelijkheden om liefde, intimiteit en seksualiteit te beleven binnen het verpleeghuis besproken. Het gebrek aan privacy en een huiselijk gevoel, praktische barrières en het gebrek aan communicatie met zorgprofessionals op alle niveaus werden hier naar voren gebracht als belangrijkste tekortkomingen.

Uit deze interviews werd duidelijk dat ondanks de moeilijke en zware periode die de partners doormaken, liefde, bescherming, loyaliteit en intimiteit belangrijke aspecten zijn in hun relatie. Dilemma's karakteriseren de thema's intimiteit en seksualiteit, en er zijn verschillende barrières aanwezig in het verpleeghuis om de liefde, intimiteit en seksualiteit te kunnen beleven zoals men dat graag wil.

Ook dit onderzoek kent de beperkte grootte en samenstelling van de steekproef als grootste beperking. Wat betreft de samenstelling is het aannemelijk dat de partners die zich hebben opgegeven wellicht het meest eenvoudig vinden om over gevoelige onderwerpen te spreken, wat niet als representatief kan gelden. Toch heeft dit onderdeel ook rijke en exploratieve resultaten kunnen opleveren die als eerste stap richting het includeren van het cliëntperspectief in onderzoek gezien kunnen worden. Daarnaast zijn er een aantal belangrijke implicaties voor de praktijk uit de resultaten te halen.

Deel C

Cliënten met dementie zijn zeer afhankelijk van zorgverleners voor zorg en begeleiding op alle gebieden van hun leven. Er wordt vanuit gegaan dat de attitudes van zorgverleners aangaande seksualiteit van invloed zijn op het handelen van deze zorgverleners, en dus op de mogelijkheden die cliënten en hun partners kunnen ervaren aangaande seksualiteit. Deze attitudes zijn dan ook van belang. In eerder onderzoek werd gevonden dat attitudes van zorgverleners worden beïnvloed door een aantal individuele factoren zoals, hun leeftijd, opleidingsniveau en de kennis die de zorgverlener heeft ten aanzien van seksualiteit bij cliënten met dementie. Een zorgverlener werkt echter nooit solitair en vanuit een eerder uitgevoerd kwalitatief onderzoek werd dan ook gesuggereerd dat organisatiefactoren, zoals organisatiecultuur, wellicht van invloed zouden zijn op de attitudes rondom intimiteit en seksualiteit.
In deze studie is middels vragenlijst onderzoek getoetst of de organisatiefactoren organisatiecultuur en de mate waarin persoonsgerichte zorg werd geboden, invloed hebben op de attitude van medewerkers van verpleeghuisorganisaties, als het gaat over seksualiteit van cliënten met dementie. Hierin is ook rekening gehouden met individuele factoren zoals leeftijd, opleidings- en functieniveau, werkgever, beleid aangaande seksualiteit, jaren werkzaam in de zorg en het gevolgd hebben van een cursus of training aangaande seksualiteit bij cliënten met dementie.

Er zijn 187 medewerkers van verschillende opleidings- en functieniveaus uit zes zorgorganisaties geïncludeerd in de studie. Het merendeel van de proefpersonen was vrouw (95,7%), had een MDO opleiding niveau 3 afgerond, had een gemiddelde leeftijd van 40,8 jaar (tussen 18-64) en ze waren gemiddeld 16 jaar werkzaam in de zorg (tussen 1-43).

Met behulp van een hiërarchische regressie analyse kwam naar voren dat wanneer er meer persoonsgerichte zorg werd verleend, de attitude rondom seksualiteit van cliënten met dementie positiever was. Ook bleek dat een meer ondersteunende organisatiecultuur ditzelfde effect bewerkstelligde. Deze effecten werden gevonden met in acht neming van verschillende controlevariabelen (kennis aangaande seksualiteit; leeftijd; opleidingsniveau; dienstjaren; zorgorganisatie; aanwezig beleid; functie; volgen van een cursus of training aangaande seksualiteit

van cliënten). Uit deze analyse kwam ook naar voren dat het aanwezig zijn van beleid ten aanzien seksualiteit van cliënten met dementie een negatieve invloed had op de attitude. Dit was in tegenstelling tot de hypothese en verwachting. In overeenstemming met de verwachting en eerder onderzoek bleek het effect van kennis op attitude groot en robuust, ook met in achtneming van alle controle variabelen.

Ook deze studie wordt gekenmerkt door een aantal beperkingen, waarvan een bijvoorbeeld in de manier van dataverzameling lag. De vragenlijsten zijn door alle medewerkers van zorginstellingen ingevuld aan het eind van een teamoverleg, wat er mogelijk voor zorgde dat medewerkers het idee hadden wel mee te moeten doen. Helaas resulteerde deze manier van dataverzameling niet in een evenredige hoeveelheid deelnemers op het gebied van geslacht. Ook in de vragenlijsten lag een beperking. Deze studie biedt echter een eerste inzicht in de effecten van organisatiefactoren als het gaat over attitudes van medewerkers ten aanzien van seksualiteit van cliënten met dementie. Deze resultaten impliceren dan ook dat, naast de bekende voordelen van het stimuleren van persoonsgerichte zorg, dit mogelijk ook voordelen heeft ten aanzien van de mogelijkheden van cliënten en hun partners om seksualiteit te beleven. Daarnaast lijkt een meer een meer ondersteunende organisatiecultuur hier ook aan bij te kunnen dragen. Beide factoren zijn echter niet eenvoudig te implementeren in een individuele zorgorganisatie. Het lijkt echter de moeite waard om te streven naar zowel het bieden van meer persoonsgerichte zorg, als een meer ondersteunende organisatiecultuur, omdat dit wellicht ook op andere aspecten binnen de zorg voordelen heeft.

Discussie

Uit de systematische literatuurstudie bleek dat het cliënt perspectief aangaande intimiteit en seksualiteit bij mensen met dementie nog niet eerder belicht was in onderzoek. Tijdens de uitvoering van het empirische gedeelte van dit onderzoek, werd er een ander onderzoek gepubliceerd met dit thema. Hierin werden op kwalitatieve wijze verpleeg- en verzorgingshuis cliënten bevraagd aangaande hun ervaringen behoeften ten aanzien van intimiteit en seksualiteit. Dit was echter een veel heterogener groep dat de onderzoeksgroep die in deze studie is gebruikt. Ook bleek uit de literatuurstudie dat geslacht van medewerkers waarschijnlijk van invloed is op de attitude die zij hebben ten aanzien van seksualiteit van cliënten met dementie.

Uit de kwalitatieve studie naar het cliënt perspectief van mensen met dementie en hun partners naar de beleving en behoeften rondom liefde, intimiteit en seksualiteit kwamen rijke thema's naar voren. Overstijgend kan gesteld worden dat voor cliënten en hun partners de thema's intimiteit en seksualiteit niet geïsoleerd zijn. Het zijn aspecten die vervlochten zijn in het (liefdes) leven van mensen, soms een plaats hebben in een zeer lange relatie.

In de literatuur worden veelvuldig vooroordelen en taboe aangehaald als het gaat over intimiteit en seksualiteit van oudere mensen en zeker wanneer het gaat over mensen of cliënten met dementie. Deze vooroordelen zijn wij tijdens de opzet en uitvoering van de studie zeker tegen gekomen, echter tijdens de interviews met de cliënten en hun partners viel dit veel minder op. Het enige echte teken van taboe kwam naar voren tijdens het bespreken van fysieke seksualiteit tijdens de interviews, waarin cliënten en hun partners in bedekte of figuurlijke bewoordingen hun beleving kenbaar maakten. Opvallend was echter dat sommige cliënten en partners echt opgelucht leken te kunnen spreken over dit onderwerp. Wellicht dat hierin wel bias schuilt, aangezien de mensen die zich hebben opgegeven voor deze studie waarschijnlijk eenvoudiger over intimiteit en seksualiteit praten.

Tot slot is het belangrijkste resultaat van de kwalitatieve studie dat liefde, intimiteit en seksualiteit, zeker nog steeds een belangrijke plaats innemen in het leven van cliënten met dementie en hun partners. Ondanks alle beperkingen, barrières, en emotionele dillema's, zijn liefde, samen zijn, loyaliteit en beschermen van de geliefde met dementie het allerbelangrijkste. Emotionele en fysieke intimiteit, op verschillende manieren geuit, bleken een belangrijke uiting van het samen zijn en de liefde voor elkaar.

Uit de kwantitatieve studie kwam naar voren dat organisatie factoren, zoals persoonsgerichte zorg en een ondersteunende organisatie cultuur van invloed zijn op de attitude van verpleeghuismedewerkers ten aanzien van seksualiteit van cliënten met dementie. Om de mogelijkheden van cliënten en hun partners om intimiteit en seksualiteit te beleven zoals zij dat graag wensen te vergroten, is het dus van groot belang in te steken op het bieden van meer persoonsgerichte zorg en een

ondersteunende organisatie cultuur. Op deze manier wordt er meer ruimte gemaakt voor een holistisch mensbeeld in de verpleeghuiszorg, wat ook op andere terreinen van waarde kan zijn.

Deze promotie studie, gepresenteerd in deze thesis, is van waarde voor wetenschap en praktijk. Ten eerste is dit een voorbeeld van de gelijkwaardige samenwerking tussen praktijk en wetenschap, wat voor beide kanten van de balans voordelen heeft. Ten tweede is het brede perspectief wat is gekozen ten aanzien van de concepten liefde, intimiteit en seksualiteit. Dit heeft het inzicht opgeleverd dat dit voor mensen geen geïsoleerde begrippen zijn, maar sterk met elkaar verweven zijn. Ten derde is deze studie de eerste die het cliënt perspectief als uitgangspunt neemt. Dit heeft rijke inzichten opgeleverd, voor zowel praktijk als wetenschap. Ten slotte blijkt het uitgangspunt van gezonde seksualiteit, ten opzichte van probleem- of onbegrepen gedrag voor meer nieuwe inzichten te hebben gezorgd. Dit heeft echter ook belet dat er een specifieker definitie geformuleerd kan worden van dit probleem- of onbegrepen gedrag, wat in de literatuur wordt genoemd als een lacune. Dit blijft dan ook nog werk voor komend onderzoek.

Er zijn echter meer beperkingen te noemen van dit onderzoek. Ten eerste vormt de gelijkwaardige samenwerking tussen praktijk en wetenschap ook belemmeringen. Zo duurt een onderzoek als dit, vanuit het praktijkperspectief, zeer lang. Wanneer de aankondiging van de start van het onderzoek achter de rug is, duurt het nog jaren, wat in de ogen van onderzoekers normaal is. Daarnaast heeft dit onderzoek aan het eind van de promotie periode nog geen direct praktisch inzetbaar stuk opgeleverd. Hieraan zal gewerkt worden na de promotie. Vanuit het wetenschapsperspectief kan gesteld worden dat dit onderzoek rijke en gevarieerde resultaten oplevert, maar te kort schiet als het gaat om theorievorming. Er wordt geen bestaande theorie of model getest, in verband met het exploratieve karakter van de studie, maar er wordt ook geen nieuwe theorie of model voorgesteld. Dit blijft ook werk voor na deze promotie studie.

Ten tweede bleek het niet eenvoudig de resultaten van de drie verschillende onderzoeksperspectieven samen te voegen. Dit was wellicht eenvoudiger geweest wanneer de volgorde van de studies anders was geweest, of er was gekozen voor een kwalitatieve studie ten aanzien van de attitude van medewerkers, aansluitend aan het kwantitatieve deel. Dit blijft liggen voor verder onderzoek.

Ten derde zijn er verschillende beperkingen te noemen die voortvloeien uit het includeren van het cliënt perspectief in deze studie. Deze zijn voornamelijk methodologisch en richten zich op bijvoorbeeld werving van de cliënten en hun partners, toestemming en het bewaken van kwaliteit van het kwalitatieve deel van het onderzoek.

Ten slotte zal vervolg onderzoek gedaan moeten worden om vragenlijsten aangaande attitude rondom seksualiteit van cliënten met dementie en organisatiecultuur te verbeteren. Dit zal ook voor verder onderzoek naar dit en andere thema's helpend zijn.

Implicaties voor verder onderzoek zijn al veelvuldig genoemd. Ook zijn er verschillende implicaties te benoemen voor de verpleeghuispraktijk. Deze zijn verdeeld in drie niveaus. Ten eerste gaat het daarbij om het cliënt niveau, waarbij de inclusie van het cliënt perspectief in de dagelijkse zorgpraktijk de eerste is. Veel zorgorganisaties spreken in hun beleid uit dat het cliënt perspectief het uitgangspunt van hun dagelijkse zorg zou moeten zijn, wanneer het echter gaat over liefde, intimiteit en seksualiteit, lijkt deze ambitie niet altijd eenvoudig te realiseren. Het verbeteren van communicatie met cliënten en hun partners als het gaat over deze thema's lijkt daarin een eerste stap. Ook een nadere bestudering van de manier waarop cliënten en hun partners zich comfortabel kunnen voelen binnen het verpleeghuis strekt aanbeveling. Ondanks inspanningen van medewerkers, bleek dit gevoel niet eenvoudig te bewerkstelligen, en bleek een gevoel van privacy meer nodig te hebben dan een gesloten deur.

Ten tweede gaat het om het organisatie niveau, waarbij het vergoten van kennis over liefde, intimiteit en seksualiteit van medemerkers een eerste stap van verbetering lijkt. Ten tweede, zoals in veel onderzoek wordt aangehaald, is het bepalen van beleid en richtlijnen ten aanzien van intimiteit en seksualiteit van cliënten van belang. Echter zouden deze gebaseerd moeten zijn op een persoonsgericht zorgparadigma, waarbij liefde, intimiteit en seksualiteit als thema's geïntegreerd zijn. Vanzelfsprekend, is het noodzakelijk dat dit beleid en deze richtlijn op een ondersteunende manier geïmplementeerd en gedragen zijn door de gehele organisatie, niet als laatste in de dagelijkse zorgpraktijk. Dit sluit aan bij de laatste implicatie, dat in het algemeen een ondersteunende organisatiecultuur, die uitgaat van het persoonsgerichte paradigma, van waarde zal zijn voor cliënten en hun partners op dit thema, maar zeker ook op andere thema's.

Ten slotte gaat het om het niveau van de dementie (verpleeghuis) zorg in het algemeen. Zoals eerder benoemd, bleek uit deze studie dat intimiteit en seksualiteit niet als geïsoleerde thema's ervaren wordt door cliënten en hun partners, maar dat deze belangrijke aspecten van het leven vervlochten zijn in hun levens- en liefdesgeschiedenis. Het besef van dit belang en deze thema's is in de Nederlandse dementie (verpleeghuis) zorg nog niet zo doorgedrongen. Mede gezien de komende generaties cliënten, lijkt het wel goed om hier meer aandacht aan te besteden. Daarnaast komt uit de complete thesis een beeld naar voren van een zorgparadigma, wat ondanks inspanningen om meer persoonsgericht te zijn, nog steeds meer beschermend overkomt. Dit heeft niet alleen invloed op de manier waarop cliënten en hun partners in de gelegenheid zouden zijn om intimiteit en seksualiteit te beleven, maar ook op zeer veel andere thema's, die mogelijk gevoelig liggen. Om een

volgende stap te zetten in een meer holistisch beeld van cliënten met dementie in het algemeen, is het noodzakelijk dat er meer ruimte komt voor het open bespreken van ethische kwesties, waarbij het cliënt perspectief niet uit het oog verloren moet worden.

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"The best friendships are built on a solid foundation of alcohol, sarcasm, laughter and a dislike of the same people"

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Curriculum Vitae

Tineke Roelofs was born on January 23, 1985 in Thorn, the Netherlands. She graduated from higher secondary general education at the sint Ursula College in Horn, in 2003. Afterwards, she graduated with a Bachelor degree in speech language therapy at Fontys Eindhoven, in 2007. Next, she studied psychology at the Tilburg University from 2007 until 2011 and obtained a master degree in Clinical Psychology. During her study, she worked as a speech language therapist in a primary care practice in Amsterdam. Moreover she worked as a care worker for people with young onset dementia in a nursing home in Eindhoven. After obtaining her master's degree she started working at Schakelring (care organization for elderly) as a psychologist. As of April 2013 she obtained an appointment as a science practitioner at Schakelring and started her PhD research at Tranzo, Tilburg University, under supervision from Professor K.G. Luijkx and Professor P.J.C.M. Embregts. This resulted in this thesis. As of January 2018 she started the post-master's health care training program (GZ-opleiding).